

# UNIVERSITY OF READING

A Qualitative Investigation of the Life Stories of Sixteen Saudi Arabian People who Stutter (PWS)

# A Thesis Submitted for The Degree of Doctor of Philosophy

Institute of Education
(Special Education, Speech and Language Disorders)

Reham Shaker Yldash Bukhari

April 2021

Abstract

Stuttering is a speech impediment that some people have to deal with in their everyday

life. Recently, greater focus has been given to the influence of stuttering on the quality of

life of individuals with stuttering. However, the lived experience of stuttering as

understood by people who stutter (PWS) has not been subjected to much qualitative

inquiry; this would enable stuttering's effect on PWS' lives—or lack of effect—and the

impediment's meaning to them to be understood.

The focus of this study is to explore the lived experience among Saudi Arabian PWS,

resolving shortcomings in the extant research through listening to the voices of PWS. The

study is framed using the Social Relational Model of Disability (SRMD) as the lens for

interpreting data.

The method of data collection and analysis was the life story approach. 16 Saudi Arabian

PWS between the ages of 18 and 57—eight women and eight men—participated in the

life story interview process.

The lived experiences of stuttering from the perspective of people who stutter involved

stories related to stuttering in educational, professional and social contexts, with educator

and parental assistance influencing the way they perceived their experience. The

participants reconstructed their life stories by adopting different types of narrative,

including narratives of difficulties, acceptance and multiple selves.

PWS' lived experience may be impeded due to their interaction with social obstacles,

insufficient assistance and negative stereotyping in the education system, work, and

domestic environments. Implications of this for how society might more positively

embrace PWS are discussed.

Keywords: Narrative Types; Lived Experience, Life Story/History; Social Relational

Model of Disability (SRMD); People Who Stutter (PWS)

Ш

# **Declaration**

I confirm that this thesis is my own work and the use of all material from other sources has been properly and fully acknowledged.

Reham Shaker Yldash Bukhari

#### **Dedication**

My thesis is dedicated to Mrs Etimad Ibrahim and Mr Shaker Bukhari, my mother and father. During all my endeavours, your enthusiasm, unconditional love and assistance has strengthened my resolve.

This research is also dedicated to Abdurrahman Alzahrani, my husband and the love of my life. Regardless of my mood and my circumstances, you have shown understanding, while also supporting me unquestioningly and dedicatedly. You have been beside me constantly, despite you being in Saudi Arabia while I study in the UK. You told me that you would wait for me all your life, which I will always remember. I am incredibly fortunate you are here for me; I love you.

To my children to come, your father and I will give you the best life possible through our efforts.

## Acknowledgements

In the Name of Allah, the most gracious, the most merciful. As stated in the Quran (39:66), 'Rather, worship [only] Allah and be among the grateful'. My gratitude and indebtedness extend to various individuals who have helped me along the path to this thesis' completion.

Firstly, Dr Naomi Flynn and Prof Catherine Tissot, my principal supervisors, were persistent, calm, passionate, reassuring, supportive and patient without bounds. I am thankful for their benevolence and unceasing assistance in the times when I confronted challenges. I would not have completed this thesis without their recommendations and guidance. All of your patience, exertion and time are things that I am exceptionally thankful for.

Also, I would like to express my gratitude to my previous supervisor Prof Jill Porter for believing in me and giving me the opportunity to work under her supervision before she retired. Her support and guidance have helped me to get a strong start and made me believe in myself even more. I will always remember the names of each of my supervisors.

All of my thesis participants deserve a special thank you, sharing their experiences while dedicating their energy and time. If they had not been committed and enthusiastic about this study, I would have been unable to complete it. Their openness in conveying their experiences, emotions and perceptions was humbling, I feel genuinely inspired by their focus on assisting other people through participating in this study. My research was markedly enhanced by their insights and they improved my own understanding considerably. It has been a privilege to get to know them. Their sincere openness, desire to help others who stutter, as well as confidence in me to treat their stories respectfully, are all things I am very thankful for. I have done my utmost to present their narratives with respect.

The University of Reading, and specifically the Institute of Education, will always have my deepest love. Improving understanding of the lived experience of stuttering has been my aim in this research, which I have attained thanks to the experience and intellectual opportunities for personal development provided by the University.

I am grateful for the attentiveness and time of my viva committee members, who offered constructive recommendations and comments having assessed my thesis.

I will always remember and be thankful for my family's unceasing assistance during my PhD research; my parents Etimad and Shaker, my sisters Ameerah, Arwa, Afnan, Reem, and Shahad, as well as Abdulrahman my brother. For their enduring assistance, reassurance, attentiveness and love, my family have my exceptional and heartfelt appreciation.

Throughout this inspiring process, I have had the continuous assistance and understanding of my husband and best friend, Abdulrahman Alzahrani. I am indebted to him and express my deepest love and gratitude. There were times I lost confidence, yet Abdulrahman continued to encourage me. His unwavering confidence, patience and believe directly enabled me to see my thesis through to the end. This thesis is our achievement, not just mine.

The financial backing that enabled me to undertake this PhD project was provided by the Kingdom of Saudi Arabia's Ministry of Higher Education and Al-Baha University, which I appreciate enormously.

My recollections and tales of PhD research in the UK will be shaped by those people I met who were gracious and warm towards me. My experience was improved unknowingly by those who smiled at me as I went about my daily life, and I thank all of them. During the coronavirus pandemic and lockdown life in the UK became very stressful for many, yet I am grateful to those who remained considerate and gracious towards me and each other regardless of the situation.

# **Table of Contents**

Chapter 1: Introduction	1
1.1: Research Context: PWS in Saudi Arabia	1
1.1.1: Stuttering's Prevalence	1
1.1.2: PWS and Saudi Society	2
1.1.3: The Impact of Stuttering on Saudi Arabian PWS	4
1.1.4: Saudi Arabian PWS and the Educational System	4
1.2: Theoretical Location	5
1.3: Stuttering: Definitions and Key Terms	7
1.4: Statement of the Research Problem	9
1.5: Personal Rationale	11
1.6: Research Questions (RQ)	12
1.7: Aims and Objectives	12
1.8: Thesis Structure	12
Chapter 2: Theoretical Perspectives for Understanding the Lived Experience of Stutt	_
2.1: Overview	14
2.2: Social Relational Model of Disability (SRMD)	14
2.2: Extrapersonal and Intrapersonal Approaches of Understanding Stuttering Experience	16
2.2.1: The Case for the Social Model of Disability	16
2.2.2: Psychological Approaches to the Impact of Stuttering	18
2.2.2.1: Studies Underpinned by Cognitive Theory	18
2.2.2.2: Studies Underpinned by Contextual Model of Coping	19
2.2.2.3: Studies Underpinned by Attitude Theory	20
2.2.3: The Ontology of Stuttering	21
2.2.3.1: Individuals' Experience	22
2.2.3.2: Labelling People as Stutterers	23
2.2.3.3: Ontology of Being Socially Disabled	24
2.3: Summary	25
Chapter 3: A Systematic Literature Review of Research in the Lived Experience of P who Stutter (PWS) and Public Attitudes toward Stuttering	_
3.1: The Lived Experiences of People who Stutter	31
3.1.1: Social and Educational Experience and PWS' Self-Identity and Concept	33
3.1.2: Social and Employment Experience and PWS' Quality of Life	35
3.1.3: The Effect of Stuttering on Social Relationships	37
3.1.4: Avoidance to Cope with Stuttering and Social Barriers	39

3.1.5: Conclusion	40
3.2: Part 2: Public Attitudes towards Stuttering	41
3.2.1: Parental Attitudes towards Stuttering	41
3.2.2: Teachers' Attitudes towards Stuttering	43
3.2.3: Children and Peers' Attitudes towards Stuttering	46
3.2.4: Public Attitudes towards Stuttering as Related to Culture	48
3.3: Conclusion	50
Chapter 4: Methodology	53
4.1: Overview	53
4.1.1: Research Questions (RQ)	53
4.1.2: Aims and Objectives	53
4.1.3: The Research Design	53
4.2: Theoretical Positionality	55
4.2.1: Ontology of Stuttering Experience	56
4.2.2: Epistemology	57
4.2.3: Axiology: Researcher Positionality	59
4.3: Qualitative Research Methods	61
4.4: Participant Selection	62
4.5: Data Collection: Narrative Life Story	63
4.5.1: Life Story Interview Design	66
4.5.1.1: Interview Topic	66
4.5.1.2: Visual Materials	67
4.5.1.3: Life Story Interview Types	71
4.5.1.4: The Effectiveness of the Data Collection Methods	73
4.6: Methods of Data Analysis	75
4.6.1: Analysis of Visual Materials	76
4.6.2: Analysis of Narrated Life Stories	78
4.6.2.1: Life History Analysis	79
4.6.2.2: Life Story Analysis (Thematic Analysis)	81
4.6.3: Analysing the Types of Narrative	
4.7: Pilot of the Interview Process	90
4.8: Trustworthiness	92
4.9: Ethical Considerations	93
4.9.1: Informed Consent and Right to Withdraw	94
4.9.2: Privacy and Data Storage	95
4 9 3. Avoidance of Harm to Participants	95

4.9.4: Duty of Care	96
4.9.5: Power Issues	97
4.10: Summary of the Research Methodology	98
Chapter 5: Findings Part 1: How do PWS Perceive their Lived Experience of St	_
5.1: Stuttering: The Concept and its Causes	
5.1.1: Personal Definitions of Stuttering	
5.1.2: Perceived Causes of Stuttering	
5.2: The Recognition of the Stutter as a Result of Social Interaction	
5.3: The Role of Family in Stuttering Experience	111
5.3.1: Positive Family Support	
5.3.2: Lack of Family Support	113
5.4: The Impact of Stuttering on Educational Life	119
5.4.1: Perceived School Support	123
5.4.1.1: Schools' Inadequate Assistance	123
5.4.1.2: School's Positive Support	
5.4.1.3: Perceptions of Teachers' Feedback	
5.5: The Impact of Stuttering on Professional Life and Career Choices	
5.6: Participants' Difficulties with Social Interaction	132
5.6.1: Difficulties in Introducing Names and Starting Conversations	132
5.6.2: Participants' Perceptions of Listeners' Reactions	
5.6.3: Bullying	136
5.6.4: The Role of Societal Awareness on Stuttering Experience	139
5.6.5: The Impact of Social Interactions with Teenagers	140
5.6.6: The Effect of Stuttering on Friendship	142
5.7: Avoidance	144
5.7.1: Avoidance of Negative Reactions	145
5.7.2: Avoidance to Prevent Being Judged by Families	146
5.7.3: Avoid Stressful Situations, and Methods of Avoidance	147
5.7.4: Perceived Avoidance as a Problem in Different Context	150
5.8: The Impact of Stuttering on Sense of Self	152
5.8.1: Elements that Led to a Low Self-Concept	153
5.8.2: Self-Concept as Affected by Age and Social Expectations	155
5.9: Treatment Limitations	156
5.10: Summary	157

Chapter 6: Findings Part 2: What Type of Narrative do PWS Adopt When Reconstructure Life Stories?	_
6.1: Narrative of Difficulties and Challenges	. 161
6.1.1: Lack of Self-Acceptance	161
6.1.2: Disclosure Difficulties	163
6.1.3: Past Social and Academic Difficulties	165
6.1.4: Childhood Difficulties	167
6.2: Narrative of Acceptance and Transcendence	. 171
6.2.1: Self-Acceptance: Accepting the Stutter	. 172
6.2.2: Self-Acceptance Resulted from Positive Challenges and Life Achievements.	. 176
6.2.3: Self-Acceptance Resulted from Having a Role Model	. 180
6.2.4: Self-Acceptance Resulted from Faith	. 182
6.3: Narrative of Conflict and Multiple Selves	. 183
6.4: Summary	. 187
Chapter 7: Discussion of the Research Findings in Relation to the SRMD	. 189
7.1: How do PWS Perceive their Lived Experience of Stuttering in Relation to the SRMD?	190
7.1.1: Avoidance Behaviours: Struggling in Silence	191
7.1.2: Effect of School Memories	194
7.1.3: Employment Stereotyping	195
7.1.4: Listeners' Reactions	. 197
7.1.5: Perceived Type of Support by Parents and Teachers	. 198
7.1.5.1: PWS' Perceptions of Families' Attitudes and Support	199
7.1.5.2: PWS' Perceptions of Schools' and Teachers' Support	201
7.1.6: Summary for Discussion of the Lived Experience of Stuttering	. 203
7.2: Discussion of PWS' Narratives of their Life Stories Over Time as Related to the SRMD	
7.2.1: The Experience of Difficulties and Challenges	. 205
7.2.2: PWS' Acceptance of the Stutter	. 208
7.2.2.1: Self-Acceptance as a Meaning of Achievements and Challenges	208
7.2.2.2: Personal Efforts in Developing Self-Acceptance	210
7.2.2.3: The Role of Faith and Role Models in Shaping PWS' Perceptions of their Experiences	213
7.2.3: PWS' Age and Feeling of Transcendence	
7.2.4: PWS' Intrapersonal Interaction and Having Multiple Selves	
7.3: PWS' Concepts of Stuttering as Related to the SRMD	. 222
7.4: Reflection on The Use of The SRMD for Interpreting Participants' Narratives	225

Chapter 8: Conclusion and Recommendations	229
8.1: Overview	229
8.2: Contributions to Knowledge	230
8.2.1: The Contribution of the Study Context and Participants	230
8.2.2: The Contribution of the Data Collection Method	231
8.2.3: The Contribution Made by this Study's Theoretical Framework in Te Reducing Negative Stereotyping	
8.2.4: The Contribution of the Research Findings	232
8.3: Study Implications and Recommendations	233
8.3.1: Stuttering Concept	233
8.3.2: Perceived Type of Support	233
8.3.3: PWS' Positive Achievements Enhanced their Lived Experience	234
8.3.4: PWS' Attitudes towards their Societies	235
8.3.5: The Stereotyping of PWS in Research Studies	237
8.4: Personal Reflection	239
8.5: Limitations of the Study	240
8.6: Future Research	241
8.7: Concluding Remarks	242
References List	244
Appendices	267
Appendix A: Studies Concerning Lived Experience of Stuttering	267
Appendix B: Studies Concerning Public Attitudes Relating to Stuttering	276
Appendix C: CASP Evaluation of Qualitative Studies (Lived Experience of St	<i>O</i> ,
Appendix D: Example of Life History Analysis	
Appendix E: Interview Transcripts	
Appendix F: Participant Information Sheet and Consent Form	
Appendix G: The Participants' Visual Materials	295

# List of Tables

Table 3.1: The Searching Terms That Used to Conduct the Literature Review	27
Table 3.2: Inclusion and Exclusion Criteria Used for Paper Identification	28
Table 3.3: The Key for Each Question in the CASP Checklist	
Table 3.4: An Example of CASP Evaluation	30
Table 3.5: The Themes Emerging from Research into the Lived Experiences of Stu	
	32
Table 3.6: Themes in Public Attitudes towards Stuttering	
Table 4.3: Study Participants	
Table 4.5: Participants' Choices of Interview Types	
Table 4.6: Data Analysis Strategy	
Table 4.8: Example for Interpretation of the Chronological Order	
Table 4.9: Summary of the Thematic Analysis Process (Braun & Clarke, 2006)	
Table 4.10: Data Coding Example for Respondent Mohammed	
Table 4.11: An Example of Analysis of a Participant's Reconstruction of their Life	•
Table 4.13: Example of Generated Themes and Subthemes	
Table 5.1: Study Participants	
Table 5.2: Findings of the Lived Experience of Stuttering	
Table 5.3: Personal Definitions of Stuttering	
Table 5.4: Perceived Causes of Stuttering	
Table 5.5: the Recognition of the Stutter	
Table 5.6: Kind of Positive Family Support	
Table 5.7: Family Lack of Support	
Table 5.8: The Negative Impact of Stuttering on Educational Life	
Table 5.9: Characteristics of Schools' Inadequate Assistance	
Table 5.10: School Positive Support	
Table 5.11: Participants Perceptions of their Teachers' Feedback	
Table 5.12: Stuttering Impact on Professional Life and Career Choices	
Table 5.13: Difficulties in Introducing Names and Starting Conversations	
Table 5.14: Participants' Perceptions of Listeners' Reactions	
Table 5.15: Perceived Experience of Bullying	
Table 5.16: The Role of Societal Awareness on Stuttering Experiences	
Table 5.17: The Reasons for Increasing the Sensitivity of PWS During their Tee	_
Years	
Table 5.18: Stuttering and Friendship	
Table 5.19: Avoidance of Negative Reactions from Peers and Teachers	
Table 5.20: Families' Negative Judgment and Reactions Led to Avoidance Beh	
Table 5.21: Avoid Stressful Situations in School and Social Sittings	
Table 5.22: The Impact of Stuttering on Participants' Self-Concept	
Table 6.1: The Type of Narrative PWS Adopted when Reconstructing their Life	-
Table 6.2: Themes Related to Narrative of Difficulties	
Table 6.6: Causes of PWS' Self-Acceptance	172

Table 7.1: Summary of the Research Finding	189
Table 7.2: Perceived School Support and Teachers' Feedback	201
List of Figures	
Figure 2.1: Social Relational Model of Disability (SRMD)	15
Figure 4.1: Overview of the Research Methodology and Methods	
Figure 4.2: Ontology and Epistemology of Stuttering Experience	56
Figure 4.4 [A]: Timeline Chart	68
Figure 4.4 [B]: Mind Map	69
Figure 4.4 [C]: Venn Design	70
Figure 4.7: Example of Visual Analysis (Participant Sarah)	77
Figure 4.12: A Simplified Example of Generating Themes (Mohammed)	87
Figure 6.3: Yasser's Visual Materials	166
Figure 6.4: Mohammed's Visual Material	168
Figure 6.5: Rakan's Visual Material	169
Figure 6.7: Tara's Visual Material	173
Figure 6.8: Haifa's Visual Material	174
Figure 6.9: Fajer's Visual Material	179
Figure 6.10: Maha's Visual Material	181
Figure 6.11: Alia's Visual Material	185

# A Qualitative Investigation of the Life Stories of Sixteen Saudi Arabian People who Stutter (PWS)

# **Chapter 1: Introduction**

This research aims to investigate people who stutter's (PWS) perceptions of their lived experiences, as well as analysing the way in which they reconstruct their life stories. The main focus of this research is to explore how these are constructed and informed by intrapersonal-external interaction. It studies the meanings that PWS give to their everyday interaction with their 'self' and external contexts (for example, at home, schools and workplaces) and how these can inform their perception of their lived experience of stuttering. The research design of this study involves a collection of qualitative data from life story interviews (Rosenthal, 1993) with sixteen Saudi Arabian PWS, eight men and eight women. The aim is to give a voice to the participants and in doing so this study uses the Social Relational Model of Disability (SRMD) to examine their experiences.

This chapter comprises seven parts. Information regarding stuttering in the specific context of Saudi Arabia is provided, followed by a presentation of the study's theoretical position. After this, stuttering definitions are discussed. Subsequently, there is the statement of the research problem, a personal rationale, after which the research questions, aims, and objectives are stated. Finally, this chapter concludes with a presentation of the current thesis' structure.

#### 1.1: Research Context: PWS in Saudi Arabia

Given that this research concentrates on stuttering experiences in Saudi Arabia, this section presents an overview of stuttering's prevalence in the country, as well as of Saudi Arabian society and educational institutions.

# 1.1.1: Stuttering's Prevalence

It has been challenging to precisely ascertain the prevalence rate of stuttering in Saudi Arabia, due to the lack of representative data. Yet, according to the Saudi General Authority for Statistics (GSTAT) (2018), it is estimated that forty thousand people over the age of fifteen have a communications and speech impediment of mild, moderate, or

severe classification (GSTAT, 2018). Even so, this proportion of people represents those with all types of communication difficulties, which may or may not include stuttering, particularly given that stuttering's severity can vary from mild to severe. Consequently, not all PWS existing nationally are recorded. Regardless, it may be posited that Saudi Arabia's percentage of PWS will not differ so markedly from other national populations. Therefore given that stuttering affects between 0.72% to 1% of the general population (Etchell, Civier, Ballard, & Sowman, 2018; Craig, Hancock, Tran, Craig, & Peters, 2002), stuttering may also affect approximately 1% of the Saudi population.

#### 1.1.2: PWS and Saudi Society

In order to establish some understanding of the Saudi Arabian context, this section provides an overview of Saudi Arabia's society and culture. Firstly, basic data pertaining to Saudi people's religion and faith will be presented, as well as an appraisal of the family's role that most Saudi citizens would have experienced while growing up. These dynamics are explored based on their potential significance in contributing to the moulding of Saudi society and culture within which this study's participants reside (Smith & Abouammoh, 2013).

As Alwhaibi, Zaidi, Alzeiby and Alhusaini (2020) have explained, Islamic religious teachings, with their significant emphasis on family focus, custom orientation and conservative norms, typically pervade Saudi Arabian society. Prior to children attaining financial independence or marriage, they will live under their parents' care. Mothers in particular have greater charge and a significant proportion of the responsibility pertaining to the domestic sphere and child rearing (Sijeeni, 2016). However, Alwhaibi et al. (2020) explained that children are expected to take on the responsibility for parental care as they become elderly. Accordingly, family and home environment expectations potentially contribute to shaping PWS' experiences.

Certain Saudi PWS have been identified as being fearful of societal stigma and negative judgments (Alghunaim et al., 2020). This may be a consequence of the tendency for the majority of Arab societies to be strongly interconnected, which may result in discomfort when somebody differs from the majority. Both familial and personal conduct in Saudi Arabian society is markedly affected by the notions of family and individual honour.

Sijeeni (2016) presented the example of how a child considered as suffering from an impairment or difficulty will be perceived as reflecting badly on their parents, with close family members usually feeling ashamed or humiliated due to their child's speech problem. Such behaviour may detrimentally affect children when they realise they can be an embarrassment to their families.

Adults' attitudes towards stuttering, including parents and teachers, has been perceived as a significant variable possibly shaping children's experiences of stuttering in Arab culture (Safwat & Sheikhany, 2014; Abdalla & St. Louis, 2014). In this regard, child-society interaction significantly affects PWS' stuttering experiences; children may learn their attitudes towards stuttering from people around them (Safwat & Sheikhany, 2014). Moreover, a child with speech impediments might become the focus of indirect negative sentiments conveyed by individuals' non-verbal expressions in response to them. As Sijeeni (2016) observed, this could exacerbate the child's self-imposition of isolation. Overall, research into Saudi public attitudes and social awareness concerning impairments indicates certain shortcomings, as Al-Gain and Al-Abdulwahab (2002) observed. Although their research was published in 2002, it continues to be cited in recent research, for example, Alwhaibi et al.,s (2020) study.

In recent years Saudi society and culture has witnessed positive changes and developments, which may reflect positively on PWS generally, as well as women who stutter specifically. For instance, the gap between men and women's autonomy has started narrowing, following years of men having greater social power compared with women (Alwhaibi et al., 2020). This includes permitting women to drive—which potentially facilitates women's independence given that they can, for example, travel to work more easily. In addition to social change and developments including the permissibility of studying abroad and social advancement spearheaded by the current monarch King Salman, can inevitably result in positive effects on public attitudes towards disability to a certain extent. Consequently, Saudi people who have lived through this social change may be expected to express more positive attitudes towards each other (and the other gender). Moreover, it could be anticipated that Saudi PWS have been influenced by the new social and cultural changes and developments, albeit insufficient research concerning this subject has been undertaken in the Saudi context.

#### 1.1.3: The Impact of Stuttering on Saudi Arabian PWS

Recent research by Alghunaim et al. (2020) has analysed the level of 'worrying' experienced by Saudi males who stutter, with the conducted survey evidencing that males who stutter endure higher levels of worry in contrast with males who do not stutter. This research hypothesised that PWS' social, educational and occupational lives will be detrimentally affected by their stuttering, while also indicating that stuttering undermines PWS' psychological well-being (Alghunaim et al., 2020). Accordingly, Alghunaim et al. (2020) established that Saudi Arabian PWS have been detrimentally affected by their stuttering, a situation congruous with that faced by PWS elsewhere. Nevertheless, focusing on PWS' challenges as being a 'fact' may once more accentuate a negative stereotype, resulting in a detrimental stigmatisation of being less competent than non-PWS within a society (Daniels, Gabel, & Hughes, 2012; Klompas & Ross, 2004).

Irrespective of Alghunaim et al (2020) research results, it may be inappropriate to state that PWS confront greater emotional challenges compared to non-PWS. It is potentially the case that PWS' concerns or challenges are connected to specific life aspects, while non-PWS hold apprehensions and face challenges linked to other life aspects. It is significant to acknowledge that myriad variables affect PWS' psychosocial welfare (O'Brian, Jones, Packman, Menzies, & Onslow, 2011). Establishing a connection between psychological problems (for example anxiety disorder) and PWS may be an intricate and sensitive subject, given that the degree of inter-causation is ambiguous. Does stuttering result in psychological problems, or is stuttering symptomatic of the psychological issue? Alongside the psychological and social challenges linked to stuttering, concerns exist regarding stuttering's effect on PWS' educational experiences and attainment.

## 1.1.4: Saudi Arabian PWS and the Educational System

The school environment may significantly affect PWS, given that they spend a substantial part of their lives in schools (Abdalla & St. Louis, 2014). Saudi students who stutter may be similar to students who stutter elsewhere, with a greater likelihood of facing limitations with regards to academic opportunities (Langevin & Prasad, 2012). In the Saudi Arabian context, this is influenced by the tendency for Saudi Arabian schools to structure their educational policy around mainstream students (non-stutterers) (Alquraini, 2011), with

no educational policy exists that details assistive interventions or strategies specifically for supporting PWS (Al-Ahmadi, 2009; Hadidi & Al Khateeb, 2015). Furthermore, teachers and peers' attitudes may be fundamental in shaping PWS school experiences.

Given the dearth of research on PWS' experiences in Saudi Arabia, research undertaken in similar Arab countries has been included here, for example Kuwait. A survey conducted in Kuwait evidenced limitations in educators' knowledge of stuttering (Abdalla & St. Louis, 2012), Kuwait's society and educational system is similar to Saudi Arabia, thus this research may be evaluated in order to estimate how Saudi teachers potentially hold similar attitudes and knowledge. Essentially, the limited knowledge school staff and teachers potentially possess regarding stuttering and how to assist PWS can result in more academic challenges for pupils who stutter and possibly exacerbates exclusion, stereotyping and stigma (Abdalla & St. Louis, 2012; Boyle, 2013).

Also, some PWS—particularly those with severe stuttering—may speak less often and have a reduced likelihood of engaging. Therefore their needs are less likely to be observed by teachers and administrators (Ginsberg, 2000). However, the responsibility to identify those needing support (and not currently identified as PWS) lies with teachers, who must have access to the appropriate support or have the option of referring them to appropriate support channels in the Saudi system. Accordingly, this study aims to elicit PWS' perspectives regarding the most effective means of supporting and addressing their requirements, which are possibly not being comprehensively addressed by schools and teachers.

To conclude, searching the literature for information regarding the influence of Saudi Arabian society and culture on understanding stuttering, it is apparent that there is a need for further studies to be undertaken inquiring into this phenomenon. The existing research is very limited and insufficient for formulating a picture of the topic of stuttering from the Saudi society's perspectives.

#### 1.2: Theoretical Location

The 'lived experience of stuttering' has been analysed in previous research through the adoption of different theoretical frameworks, varying from theories connecting the

experience to the person who stutters, to theories emphasising the role of social barriers in the lived experience of stuttering (Isaacs & Swartz, 2020a). Through appraising literature pertaining to stuttering, it is apparent that the majority of studies concentrate on how people's lives are affected by stuttering, with such studies adopting a personal construct theory approach (Isaacs & Swartz, 2020a). Thus, some studies perceive the stuttering condition as affecting PWS (for example Daniels et al., 2006; Corcoran & Stewart, 1998; Kathard, 2006; Kathard, Norman, & Pillay, 2010; Klompas & Ross, 2004).

Other researchers have positioned stuttering as viewed in accordance with the social model of disability (SMD), through which stutterers find themselves incapable because of social forces. The social model literature has thus far concentrated on assessing how negative social interactions, for example bullying, negative attitudes and unhelpful responses, affect stutterers (Abdalla & Louis, 2012 & 2014; Bailey, Harris, & Simpson, 2015; Al-Khaledi et al., 2009; Boyle, 2013). Such studies propose that the challenges confronting PWS result directly from social variables. While no investigations have been found, to date, assessing how stutterers react to external factors-including social factors—given that social factors cannot affect an individual without that person responding to those factors. To fill this gap, a theoretical framework combining theories concentrating on individuals' abilities with theories of social barriers of disability was selected as appropriate for investigating the lived experience of stuttering. Specifically, this framework is the Social Relational Model of Disability (SRMD). Reindal (2008) provides an explanation of the SRMD framework as seeking to explore the phenomena of disability, impairment (personal ability) and impairment effects. Further discussion of the SRMD and research rationale for adopting the SRMD is presented in Chapter 2.

This theoretical framing of this research contests the 'Social Model of Disability' (SMD), and replaces it with the Social Relational Model of Disability (SRMD, otherwise known as the interactional model) as a means of obtaining a comprehensive understanding of how individuals, as well as their personal and internal characteristics, interrelate with external elements in framing their personal experience (Reindal, 2008; Thomas, 2004). On this basis, this research adopted the SRMD as a means of formulating a comprehensive understanding of how PWS interrelate their personal, internal characteristics with external elements, during the process of understanding and apprehending their stuttering

experience. The SRMD is used in this research to argue that certain PWS may show greater inclination to be affected by their social environment, compared with others who seem less affected by their social surroundings. This study considers PWS' lived experience of stuttering to be a construction of their intrapersonal-social interactions.

### 1.3: Stuttering: Definitions and Key Terms

Initially, I wish to clarify that I do not consider stuttering to be a disability or disorder. Rather, stuttering is deemed to be a 'different' manner of speech or type of speech difficulty, classified as a (potential) restriction depending on the difficulties that individuals potentially encounter (and feel) during their engagement in social interactions and with their environments. Accordingly, the external barriers that PWS may need to cope with, alongside how PWS derive meanings from these barriers, may determine the stuttering's effect on PWS.

In the extant literature, stuttering is defined as a complex, multidimensional and subjective set of phenomena, potentially including non-fluency, personal wordrepetitions, prolongation (Jackson, Quesal, & Yaruss, 2012), alongside automatic alterations to tempo, stoppages, irregular breaks, or extended periods of incoherence (Bloodstein, 1995; Guitar, 2006). Secondary actions may accompany stuttering, for example eye flickering, jaw twitching and automatic head movements, in addition to the development of coping mechanisms such as avoidance (Swartz, Irani, & Gabel, 2014). Stuttering's aetiology has also been the subject of some research interest. Approaches range from the biological—for example the proposition that development deficiencies in the audio-phonetic anatomy and/ or involuntary constriction of the larynx (Belyk, Kraft, & Brown, 2015)— to environmental factors, in order to explain the emergence of a stutter (Hamoum, 2016). Moreover, psychological approaches have proposed a connection between stuttering, fear and anxiety (Iverach & Rapee, 2014). Key variables are thought to include psychological issues, innate qualities, gender and natural effects (Prasse & KiKano, 2008). To the best of this researcher's knowledge, a thorough comprehension of the relevant cognitive and environmental variables remains elusive (Panico, Healey, Brouwer, & Susca, 2005). Consequently, it is problematic to derive a universal definition.

Stuttering is understood to be a multidimensional experience stemming from a complex interaction between environmental, psychological and cognitive, as well as behavioural factors (Bothe, Davidow, Bramlett, Franic, & Ingham, 2006). This approach amalgamates the biological and psychosocial approaches, positing a reflexive relationship between the underlying physiological and environmental variables, where developmental factors perpetuate the environmental ones (De Nil, 1999). As Snyder (2001), proposed, a shift has occurred in the manner of appraising stuttering, from its perception solely as a speech disfluency to pursuing a clarification of the nature of it as a social phenomenon, which may facilitate the reduction of negative social stereotyping and stigma in individuals' experience of stuttering.

In accordance with the field literature, it is evident that a desire exists to define stuttering as a multidimensional phenomenon, however, this has remained unfulfilled in research studying PWS' lived experiences (Isaacs & Swartz, 2020a). This is due to the fact that stuttering definitions in the majority of studies are typically linked more substantially to scientific clarifications of the condition's characteristics, for example repetitions and prolongations (Jackson ,Yaruss, Quesal, Terranova, & Whalen, 2015). Such academic definitions aim to define the stuttering condition, through which PWS and non-PWS are distinguished (Tichenor & Yaruss, 2018). However, such definitions have not paid attention to the personal aspects of the experience. These personal aspects of the concept of stuttering include PWS' thoughts and narratives regarding their previous and present stuttering experiences.

This study argues that individuals' concept of stuttering may be adopted as an approach to establishing knowledge relating to the meaning that PWS ascribe to their stutter, given that it links to them and their lives specifically. Thus, the stuttering concept, as defined by academics working in the field, is unlikely to adequately represent the ideas of PWS which can differ widely according to age, education level and so forth (Tichenor & Yaruss, 2018). In this regard, it is appropriate to provide a consistent identification and meaning to certain key terms revolving around stuttering as understood in this study.

Coping with stuttering: Lazarus and Folkman have described coping as 'cognitive and behavioural efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person' (Lazarus & Folkman, 1984). In this

study coping with stuttering refers to the means, methods and strategies employed by PWS (consciously or subconsciously) to live with stuttering that limits the perceived negative consequences on their social, academic and professional lives.

Avoidance behaviours are coping strategies that some PWS adopt, in which they may isolate themselves from others and avoid participating in social activities. These avoidance behaviours can occur when PWS limits communication with others to hide or mask their stuttering and steer clear of stressful situations that result from stuttering, such as receiving negative feedback from listeners (Plexico, Manning, & DiLollo, 2005).

Social and cultural: The terms social and cultural used in this study refers to the factors that relate to the environmental and contextual elements that can affect PWS' educational and professional experience and performance. The social and cultural factors can include educational and professional policy and practice, social interaction and relationships, nonstutterers' responses and reactions, and societal attitudes towards stuttering and stutterers. In addition, social and cultural factors can include the 'social role' which refers to the typical tasks that the individual has fulfilled (or is required to fulfil) in within their community (Johnson, Avenarius, & Weatherford, 2006).

In summary, for the purpose of this thesis, stuttering is perceived as a speech impediment linked to behaviours such as coping mechanisms and avoidance, while it may also be influenced and affected by social and cultural contexts. The definitions and key terms required explanation in this introduction because they will be mentioned throughout the thesis. The following section provides a statement of the research problem that has been generated having appraised the existing research in the lived experience of stuttering field.

#### 1.4: Statement of the Research Problem

PWS' personal variation in their impediment experiences were overlooked in previous research studies (Isaacs & Swartz, 2020a). Previous researchers have typically concentrated on stuttering's negative effects (see Yaruss & Quesal, 2004; Klompas & Ross, 2004), possibly resulting in adverse stereotyping of PWS, while neglecting the individuals' role in shaping their experience. The majority of studies have analysed

stuttering's negative effect on PWS, alongside an exploration of public attitudes regarding stuttering and PWS (for example, Craig, Blumgart, & Tran, 2009; Crichton-Smith, 2002; St. Louis et al., 2016; Klompas & Ross, 2004). More specifically, studies have reported that varied aspects of PWS' lives are negatively affected by their stuttering, including social, educational and quality of life aspects. Among these studies, insufficient research has studied how PWS understand and derive meaning from their stuttering experience. Essentially, limited research has appraised what elements possibly contribute to making PWS perceive their experiences as negative or positive. Therefore, there is a gap in the research literature regarding the type and nature of the challenges faced, if there are difficulties at all, in PWS' experience, as a means of avoiding bias and stereotyping when creating PWS' knowledge of experiences. Furthermore, numerous studies have focused on collating and comparing public attitudes among countries (for example Abdalla & St. Louis, 2014). Nevertheless, little research has connected public attitudes to such attitudes' effect on individuals. Consequently, this study concentrates on how Saudi Arabian individuals perceive their stuttering experiences, as well as how they reconstruct their narrated experience as being negatively or positively affected by their stuttering and social interactions.

In contrast with the majority of research studies in the stuttering field, this study does not consider PWS as a fixed and/or stereotyped group (Ellis & Hartlep, 2017). Instead, it perceives PWS' experiences as a matter pertaining to individuals, which has been shaped throughout their specific life context and social interactions. Numerous studies have covered stuttering experiences' quantitative aspects, which have been primarily classified based on stuttering's effect on PWS' experience (for example, Adriaensens, Beyers & Struyf, 2015; Erickson & Block, 2013). Thus, quantitative research may not facilitate the clarification of details of PWS' experiences, given that insufficient emphasis is placed on participants' use of language and words as a means of expressing themselves or to discuss meaningful aspects of their experience, for instance reasoning, feelings and stories (Stewart & Richardson, 2004; Connery, McCurtin, & Robinson, 2019). Consequently, a qualitative research paradigm was adopted to allow more effective exploration of PWS' stuttering experiences as individuals as opposed to as a group. In this regard, the research findings do not aim to generalise the results, instead the aim is to understand those individuals who participated in this research. Subsequently, the results concerning individuals' experiences may be linked to the wider body of research.

Also, a substantial amount of research has been conducted with non-PWS regarding their attitudes and knowledge towards PWS, whereas scant research has directly investigated PWS' views and attitudes (Connery, McCurtin, & Robinson, 2019). Research that does assess PWS' experiences (for example, Corcoran and Stewart, 1998; Daniels and Gabel, 2004; Klompas and Ross, 2004) has narrowly focused on males who stutter. Thus, the majority of studies have been conducted with more male than female participants (Nang et al., 2018; Adriaensens et al., 2015). Therefore, insufficient research studies have been conducted with females who stutter (Nang et al., 2018). Consequently, including both genders in this study may contribute to addressing this research gap.

PWS' lived experiences is a prominent subject that has received focus in certain extant studies but the perspective of PWS is under-represented and under-researched. Therefore, the aim of this thesis is to establish and clarify a comprehensive perspective of PWS' lived experiences by giving a platform for their voices. The life story method has been adopted with the aim of collecting data concerning how the Saudi Arabian participants (both men and women) perceive, as well as what they feel about, the effect of stuttering on their overall lives and everyday contexts. This will contribute to filling the gap in the literature regarding Saudi PWS' stuttering experiences.

#### 1.5: Personal Rationale

The subject of lived experiences of stuttering represents an extension of my own work undertaken during previous research projects at Bachelor's and Master's level. My specialism is in 'Speech and Language Disorders', therefore I decided to concentrate specifically on stuttering due to it being one of the most common speech problems that people experience, compared with other type of speech disorders (McKinnon, McLeod, & Reilly, 2007). Furthermore, I have a longstanding interest in understanding how any of us are constructs that are a product of our social interactions. For example, we grow up holding certain beliefs about ourselves and the world around us, which have been moulded since an early age. These beliefs may include things that are evidently inherited from society, for example religious beliefs, although it may also comprise beliefs relating to our abilities and satisfactions in life. Therefore, I am concerned with investigating how PWS understand and respond to external factors that influence them, as well as how their understanding of their interaction may shape their self-perceptions and their experience.

I am interested to know whether PWS are aware that society has affected them detrimentally, as well as whether they can make changes or mitigate such negative effects. Therefore, my main aim through conducting this study using a life story method is to elicit PWS' voices and seek to diminish negative stereotypes.

#### 1.6: Research Questions (RQ)

- RQ1. How do PWS perceive their lived experience of stuttering?
- RQ2. What type of narrative do PWS adopt when reconstructing their life stories?
- RQ3. To what extent can the Social Relational Model of Disability (SRMD) conceptualise the elements that shape PWS' expression of their life story with stuttering?

# 1.7: Aims and Objectives

- 1) To elicit PWS' voices regarding their experiences through adopting the narrative life story method, alongside collection of visuals materials.
- 2) To connect the SRMD with issues related to PWS' lived experiences.
- 3) To devise a framework offering tangible and practical proposals for the improvement of PWS' social, academic and professional experiences and well-being.

#### 1.8: Thesis Structure

This chapter has presented the general background to the research, comprising definitions and an overview of the characteristics of Saudi Arabia's society within the context of stuttering-related speech difficulties. Subsequently, Chapter 2 will aim to assess the philosophical perspectives for understanding the experience of stuttering, involving a review of the policies and practices pertinent to the field. This is followed by a systematic literature review of the extant literature related to PWS presented in Chapter 3. The methodology is discussed in Chapter 4. In Chapter 5 and 6 the findings are presented, while Chapter 7 discusses the implications of these findings. In the final chapter (Chapter 8) the commentary makes clear the original contribution that this study makes, it also reflects on the limitations of the study and implications for future research.

# Chapter 2: Theoretical Perspectives for Understanding the Lived Experience of Stuttering

#### 2.1: Overview

This chapter focuses on the main theoretical perspectives related to the experience of stuttering. The literature review for this thesis is deliberately divided into two chapters in order to make clear: the theoretical frameworks underpinning this study, and their relationship to PWS; and the extant literature in the field relating to PWS. This chapter is divided into three main sections: firstly, a dissection of the Social Relational Model of Disability (SRMD), which is employed here as a framework for conceptualising individuals' experiences of stuttering. Secondly, a review of both extrapersonal and intrapersonal approaches of understanding stuttering experience. The third section provides an ontology for the experience of stuttering.

### 2.2: Social Relational Model of Disability (SRMD)

The SRMD is defined as a platform for understanding the experience of the impairment effects as arising from the interactions between complex and diverse aspects (Reindal, 2008; Thomas, 2004). These include (i) intrapersonal elements (individuals' differences and the characteristics of the individuals), such as their needs, coping abilities, confidence levels and motivation, and (ii) external factors, which can include social, cultural, political and environmental features (e.g. adverse societal attitudes and stereotypes) (Reindal, 2008; Thomas, 2004). Based on the SRMD, the interactions between the individual who stutters and their social, cultural, and physical characteristics can determine self-perceptions of stuttering and its impact. The SRMD, therefore, offers a social relational model for understanding the challenges faced by stuttering individuals. Thus, the negative consequences of having a speech impediment may only be encountered by those for whom environmental interactions produce negative outcomes. These negative outcomes can include labelling, social exclusion, discrimination and negative stereotyping (Reindal, 2008). These outcomes, which are generated from intrapersonal-external interaction, can be understood in different ways, depending on the meanings that individuals give to their interactions within their environments and with one another (Reindal, 2008; Plummer, 1990).

Figure 2.1 is a visual representation of how the SRMD is understood in terms of this study. It shows that there are two overlapping elements of the experience of stuttering: one of them represents the person's understanding of their internal elements including their abilities, and their identity as 'stutterers'; the second circle represents the external elements and the person's understanding of external elements. External elements are how PWS perceive and understand others and the world around them.

Intrapersonal Lived External Experience of Stuttering

Figure 2.1: Social Relational Model of Disability (SRMD).

Intrapersonal-external interactions can shape how PWS and those around them understand and give meaning to the experiences of stuttering and ultimately label PWS as 'stutterers' (Kathard 2003; Constantino et al., 2017). Thus, understanding stuttering as a speech impediment can be constructed from social interactions, in which people in society, including people who stutter, may build their knowledge about the experience of stuttering (Adriaensens et al., 2015; Erickson & Block, 2013; Hertsberg & Zebrowski, 2016). In other words, social and cultural elements can generate the impact of a condition rather than being responsible for making the condition. This aligns with the SRMD and social studies that distinguish 'impairment' from 'disability'. The impairments are the physical condition while the disability is the negative affect of the impairments (Reindal, 2008), which can be caused by people's interaction with social and environmental barriers (Shakespeare & Watson, 1997).

Since individuals make meanings thorough their social interactions, Symbolic Interactionism (Plummer, 1990) is generally linked to the SRMD. Symbolic Interactionism can be a key in PWS' lived experience, since, for all humans, 'interactions' and 'communication' are everyday events that people engage in. For most people this is taken for granted, while for people with speech impediments it can be of heightened significance to their life experience (Acton & Hird, 2004). Many PWS indicate that the most difficult part of their experience of stuttering is when they stutter in their social interactions with others (Nang et al., 2018), as well as their intrapersonal interaction when they evaluate and make sense of their difficulties in social circumstances (Nang et al., 2018). Consequently, this study has implemented the SRMD framework to examine stuttering experiences as being shaped by the individuals' personal and social interactions. The subsequent section analyses both the extrapersonal and intrapersonal framework of the stuttering experience.

# 2.2: Extrapersonal and Intrapersonal Approaches of Understanding Stuttering Experience

In order to gain an insight into the factors that might shape the individuals' experience, studies that are underpined by the extrapersonal approaches and the intrapersonal theories and frameworks will be examined through the lens of the Social Relational Model of Disability (SRMD). Extrapersonal approaches are referred to as the Social Models of Disability (SMD), while the intrapersonal frameworks are referred to as psychological approaches to understanding the impact of stuttering, such as Cognitive Models of Speech Production, Contextual Models of Coping, and Attitude Theories.

# 2.2.1: The Case for the Social Model of Disability

This section returns to the Social Model of Disability (SMD), which will represent the external dynamics of a person's interaction as appearing in this study. Initially, it may be worth distinguishing between the SMD and SRMD. The SMD argues that the challenges confronting impaired people directly result from social and environmental obstacles (Oliver, 1996, 2013), whereas the SRMD is interested in the relationship between intrapersonal and external elements that can result in negative impairment effects (Reindal, 2008).

Thus, the SMD regards the experience of disability as a product of the structure or organisation of a society, rather than the individual difference or impairment (Oliver, 2013). Under this approach, therefore, not all persons with impairments are necessarily disabled. This model proposes that disability is an externally produced construct (i.e., caused by physical, economic, and social barriers) distinct from the underlying condition (Bailey, Harris, & Simpson, 2015). Therefore, based on the SMD, it could be argued that social and cultural features can account for the difficulties and barriers that PWS encounter in social, educational and professional life. For example, non-stutterers' negative attitudes toward PWS can involve negative stereotyping, judgements and labelling (Boyle, Daniels, Hughes, & Buhr, 2016). Such attitudes might lead to creating a negative educational environment that impacts PWS' educational performance, according to the Social Model of Disability (SMD) (Bailey, Harris, & Simpson, 2015). While, hypothetically, if no one reacts to stuttering negatively, then stutterers may not face these difficulties and consequently are safeguarded from disabling environmental elements.

However, the SRMD moves beyond the SMD in recognising that it is difficult to separate impairment and the phenomenon of disability (Reindal, 2008). Therefore the investigation of this study draws upon the SRMD because it can offer a more integrated approach to the phenomenon of stuttering. The impact of social factors needs individuals to respond in order to shape the individuals' experience of their internal differences. Thus, it can be difficult to separate out the influence of the external factors and the intrapersonal elements in relation to how they affect individuals. For example, the most significant social barriers for PWS can be their fears and concerns about non-stutterers' attitudes towards them (Lowe et al., 2012). These fears and concerns can be learnt from previous negative experiences of social interaction between PWS and their societies (Fraser, 2002). The result of previous negative social attitudes may power social exclusion: i.e., either by the society itself (e.g., stigma-driven exclusion) or by volition on the part of PWS (e.g., avoidance behaviours in pre-emption of negative appraisals). Social- and self-appraisals are reciprocally informative (Klompas & Ross, 2004). It is not expected that all PWS will be affected in the same way, but the impact can be influenced by individuals' characteristics and differences. Again, this underscores the value of the SRMD over others, including the SMD. But this is not the entire story, as individuals also construct meanings which are important to explore. The following section discusses the personal aspect of the experience of stuttering.

#### 2.2.2: Psychological Approaches to the Impact of Stuttering

Since this study seeks to understand individuals' experience of stuttering through the meanings that individuals reconstruct about themselves, and their interaction with external elements, there is a need to consider some of the theories and models that relate the experience of stuttering to the individuals. This is to gain an insight into the intrapersonal parts of the interaction which might, under the SRMD perspective, play a role in the persons' experience. The following, therefore, looks at the intrapersonal models which consider stuttering as a condition produced by the individuals' genetic and neurological mutations and therefore requiring clinical treatments (Kang et al., 2010). This section discusses three psychological theories that were commonly linked to stuttering: Cognitive Theory, Contextual Model of Coping and Attitude Theory.

# 2.2.2.1: Studies Underpinned by Cognitive Theory

The Cognitive Theory of stuttering pathologises individuals by viewing PWS' experience of the impediment as by-products of mental processes; particularly, via emphasis on PWS' cognitive abilities, including stutter control and management and speech-related stress (van Lieshout, Ben-David, Lipski, & Namasivayam, 2014). Rather than focusing on the need for social change, awareness and removing barriers, this theory takes the approach that to remove the hindrances in individuals' abilities, these individuals need to modify their mental state to accommodate social expectation (Oliver, 1996). Cognitive accounts might be useful, as they provide a framework for discussions linking attainment with PWS' coping strategies; particularly, with reference to social, school and workplace contexts (Vanryckeghem, Brutten, Uddin, & Van Borsel, 2004; Plexico, Manning, & DiLollo, 2005). However, in these contexts, an understanding of the stressors (and the provision of support that mediates them) can minimise negative impacts (Roeser, Eccles, & Freedman-Doan, 1999; Maxwell, 1982). This being said, while Cognitive Theory can explain some of the psychological issues impacting PWS' lives, we must also consider the role of social interaction (Gergen, & Davis, 1985). For example, a stuttering individual's fear of negative social evaluations can compound and amplify pre-existing social anxieties (Mulcahy, Hennessey, Beilby, & Byrnes, 2008) and exacerbate the existing cognitive-related difficulties associated with speech.

Therefore, the SRMD views that stuttering should not be regarded as a medical disability; but a bio-psycho-social condition in which some PWS may experience social anxiety and/or depression, a sense of dread and/or weakness, and feelings of diminished self-esteem (e.g., being a disappointment to their families) (Erickson & Block, 2013). It follows that these negative feelings and psychological conditions might be learnt and constructed from and through the interaction between PWS and their social environments (Al-Khaledi et al., 2009). Thus, the cognitive experience of stuttering can be conceptualised as a result of social and cultural interactions.

This study can implement the Cognitive Theory as an aspect of the SRMD framework, on the basis that the SRMD is also concerned with the stuttering condition's direct effects on individuals' experiences, which are referred to as 'impairment effects' (Thomas, 2004). Accordingly, the interaction between the individual's biological condition and social environment remains of significance to the SRMD theorists, with the SRMD being the approach applied in this thesis. In light of this point, the cognitive theory can significantly be linked to the Contextual Model of Coping, in terms of how some PWS might psychologically respond and cope with the external stressors, as is discussed next.

# 2.2.2.2: Studies Underpinned by Contextual Model of Coping

Lazarus and Folkman (1984) define the Contextual Model of Coping as a way of conceptualising the relationship between stress, appraisal and individuals' abilities of coping. This is not a theory as such but a useful model that views coping as a process to actively manage a stressful situation, through environmental, situational, and coping style appraisals (Folkman & Lazarus, 1990; Lazarus & Folkman, 1984). An appraisal is a process of making a judgment about a specific condition and/or experience (Plexico, Manning, & Levitt, 2009a). These appraisals can be influenced by motivation, self-concept, and world-concepts, as well as their past experiences (Plexico et al., 2009a). However, this model fails to take into account the influence of removing environmental barriers on coping abilities.

The Contextual Model of Coping examines both problem-focused (i.e., where conditions are controlled on the basis of motives, beliefs, and efforts) and emotion-focused coping skills (Plexico et al., 2009a; Carver, Scheier, & Weintraub, 1989). For stutterers, emotion-focused coping may be employed in stressful situations. However, these approaches can entail avoidance behaviours, such as gaze-aversion in pre-emption of negative judgments, for example (Plexico et al., 2009b). A review of the literature highlights the essential role played by coping strategies in moderating the relationships between stress and physical and psychological well-being. In line with theories of social cognition, PWS might avoid stressful situations so as to manage social anxieties (Bandura, 1989).

The contextual model indicates, therefore, that coping is based on personal motivation and situation-based strategies, which can be related to the interpretation of the data in this study. This research argues that the Contextual Model is strongly aligned with the SRMD as interpersonally affected, given that PWS may struggle to cope with stuttering resulting from contextual barriers (Thomas, 2004). Such contextual barriers (for example the dearth of social support and inappropriate teaching strategies) may affect PWS' coping performance (Lakey & Cohen, 2000). Therefore, the contextual barriers, as well as how PWS derive meanings and deal with these barriers, are of interest in this research.

# 2.2.2.3: Studies Underpinned by Attitude Theory

The third relevant theory is Attitude Theory, which is defined as people's overall evaluation and perceptions of an object resulting from serial judgements (Pratkanis, Breckler, & Greenwald, 2014). This may explain the processes of stereotype formation in both stuttering and non-stuttering populations. It notes that positive self-attitudes including PWS' self-acceptance can be associated with a higher quality of life (Plexico et al., 2005): this could potentially encourage participation in social interactions without the need to conceal a stutter (Plexico et al., 2009b). Attitude Theory can also provide a basis for understanding how PWS become self-critical and avoidant. That might be a process that begins with exposure to serial, negative judgements that lend to altered (and unhealthy) self-appraisals that, in turn, may lead to making PWS avoid social interaction and participation in social, educational and workplace settings.

In the SRMD, this is called self-imposed restrictions (Thomas, 2004). It is understood that attitudes towards stuttering, held by non-stuttering individuals, can influence PWS negatively (Holton & Edmondson, 2015). Negative attitudes and feedback can undermine self-esteem and self-perceptions of competence. Stigmatisation, such as negative stereotyping (i.e., associating stuttering with diminished intelligence and competence) may affect social well-being, educational performance and professional performance adversely (Holton & Edmondson, 2015; Albarracin, Johnson, & Zanna, 2014). Regarding the SRMD perspective, the social attitude of stuttering and PWS remains a fundamental consideration that may establish a negative self-attitude towards PWS.

In conclusion, the SRMD's adoption in this thesis as a framework for understanding the stuttering experience provides a breadth of perspective, including both the impairment, its effects, as well as the social and environmental effect on PWS' self-perceptions and perceptions of their experience of stuttering. Having discussed the various theories connected to stuttering, the subsequent sections provide further in-depth assessment and clarification of the ontological position regarding stuttering experiences, whether this experience exists, in addition to the construction of such experiences.

# 2.2.3: The Ontology of Stuttering

The term *Ontology of Stuttering* is used here to explore how the experience of stuttering is constructed. Based on the Social Relational Model of Disability (SRMD), the experience of stuttering is a construction that is created throughout intrapersonal-external interactions, and it will only be understood through individuals' narratives about how they make meanings of their experience (Reindal, 2008). The elements that are involved in reconstructing the experience of stuttering are highly complex because it is an individual's experience that is linked to themselves and their understanding of social interaction (Acton & Hird, 2004). However, there is limited research that has explored the ontology and epistemology of stuttering experience from PWS' point of view (O'Dwyer, Walsh, & Leahy, 2018).

Understating the experience of stuttering through social interactions can be more appropriate than considering the experience of stuttering as a biological construction. This

is because the stuttering condition is one of the most difficult issues to diagnose and to distinguish (Teesson, Packman, & Onslow, 2006; Murphy, Quesal, & Gulker, 2007). For example, in most cases the level of stuttering is changeable depending on age, contexts and situations (Nang et al., 2018); there are times when PWS do not stutter at all or manage to reduce their stuttering. For instance, stuttering may not always exist when PWS think or talk in their head. Some PWS say that their stutter increases when they speak in front of other people more than when they speak alone (Carter et al., 2017). In addition, some PWS manage to control their stuttering by adopting strategies and techniques such as breathing (Ellis & Hartlep, 2017) or even thinking about ideas that take their focus away from stuttering so they manage not to stutter (Arnold, Conture, Key, & Walden, 2011).

Thus, if there are brain or neurological problems, the question remains how people manage to speak without stuttering on some occasions, such as when they are alone or when they are not in a stressful situation. If stuttering is considered as a disorder that exists within individuals' brain or speech mechanisms, how can stuttering be influenced by the contexts or by behavioural strategies that control stuttering? Therefore, this study argues that stuttering is not a disorder that exists all the time, but it is individuals' experiences that can be influenced by external factors that encourages stuttering to appear. The ontology of stuttering can, therefore, exist through intrapersonal-social interactions in which PWS and their societies and culture are included. The following sections discuss the ontology of stuttering within individuals' experience, social labelling and social disabling.

# 2.2.3.1: Individuals' Experience

It might follow logically then to define the ontology of stuttering through individuals' understanding of the experience of stuttering and its reality (Acton & Hird, 2004). Stuttering experiences can be constructed through a complex procedure that involves people's emotional and psychological reactions to intrapersonal-external interactions. Such procedure can determine how people make sense of a phenomenon related to self and others (Clark, 1987; Iser, 2013). Therefore, our understanding about stuttering is generated from 'people', both individuals who experience stuttering and their listeners

(society) who may identify people's speech as stuttering (Tichenor & Yaruss, 2018). Thus the ontology of the stuttering experience is first understood through individuals' knowledge, feelings and interpretations of the stuttering moments (Tichenor & Yaruss, 2018; Gabel, 2005; Etchell et al., 2018).

Stuttering is something that is felt and experienced by the person with a stutter rather than being clinically measured or attributed to biological differences. For example, studies have linked stuttering with the idea of anticipation of stuttering, so that when a person with a stutter feels, expects and thinks he or she is going to stutter, that increases the likelihood of stuttering (Jackson, Yaruss, Quesal, Terranova, & Whalen, 2015; Bowers, Saltuklaroglu, & Kalinowski, 2012). PWS' anticipation of stuttering can be generalised from stuttering-related anxiety or fear based on prior experiences (e.g., Plexico et al., 2005, 2009a; Beilby et al., 2013; Yaruss & Quesal, 2004). Only individuals who stutter can know and understand their own experience of stuttering and how and when stuttering appears. In addition, they can understand what stuttering means to them and to their lives. They can locate where stuttering stands in their lives, and to what extent stuttering exists or temporarily exists or if they believe that stuttering does not exist at all. Moreover, people who experience stuttering may give clues as to how stuttering exists within their own identities and lives (Kathard, Norman, & Pillay, 2010). As relevant to this thesis, examining the words they use to identify themselves and describe stuttering, and the meanings they give to their experience of stuttering, could enhance researchers' and other people's understanding of the extent to which stuttering essentially exists in one's life (Daniels, Hagstrom, & Gabel, 2006; Bricker-Katz, Lincoln, & Cumming, 2013).

#### 2.2.3.2: Labelling People as Stutterers

The knowledge of the condition of stuttering can be attributed to the behaviours of stuttering that appear from the person with a stutter and a behaviour that a listener can identify (Tichenor & Yaruss, 2018) and label as stuttering. PWS are stigmatised as different and less fluent people when compared to people who do not stutter (Constantino et al., 2017; Erickson & Block, 2013; Hertsberg & Zebrowski, 2016). Such social interaction can highlight and label people's differences; as a result, the way PWS talk is labelled as 'stuttering'. Therefore, the negative experience of stuttering may not exist

outside these social interactions and comparisons. This point raises the issue that stuttering as a behaviour can be encouraged by society's labelling: it might have started from a point in the past where the person stuttered in front of people, and he or she realised this stutter, and the people around them labelled, reacted and commented about stuttering. This event reinforces the term leading PWS to believe that they do stutter and over time they might face difficulties to overcome the stutter; because when they understood that they stutter this made it difficult for them to change this belief in their subconscious (Hertsberg & Zebrowski, 2016; Jackson et al., 2015; Walden & Lesner, 2018).

# 2.2.3.3: Ontology of Being Socially Disabled

The experience of stuttering has a social and cultural basis for its ontology, which is linked to the subject of a disabling society and culture (Shakespeare, 1994). Disabling society and culture refers to external factors, including environments, societies and cultures that surround people with a specific physical, mental or psychological condition and create difficulties and challenges when the person is interacting with this disabling culture. In a disabling society and culture, the existential negativity associated with being a person with a condition such as stuttering can come at the expense of self-concept as incapable or 'disabled' (Kathard 2006; Kathard et al., 2010; Shakespeare, 1994). Thus, disabling social and cultural environments within families, schools and workplaces can deter and shape people's experience of stuttering (Daniels et al., 2012).

This view of the ontology of stuttering is congruent with the SRMD, in which stuttering is seen as an experience that is constructed from the interaction between intrapersonal and external elements: intrapersonal can include individuals' differences and abilities, and external factors can be related to social and cultural aspects (Thomas, 2004; Shakespeare, 1994). Therefore, a recent study has argued that speech therapists' interests should shift from focusing only on helping PWS to control and reduce their stutter to supporting them to adopt strategies for enhancing their listeners' understanding (Maxfield & Ferreira, 2019). This turns the focus away from PWS to their non-PWS listeners who have been taking a significant role in the current understanding of stuttering (Tichenor & Yaruss, 2018; Plexico et al., 2005; Nang et al., 2018). This idea is aligned with this study's perception of defining the stutter, because it argues that the stutter becomes a problem

only in the event that it detrimentally affects PWS' personal and social lives. Therefore, removing social and communicational barriers (for example social labelling or being misunderstood by listeners) may support PWS with coping with their stutter and enhancing their experiences.

#### 2.3: Summary

In conclusion, the SRMD (Thomas, 2004; Reindal, 2008) can provide a holistic framework to understand the role of PWS' interactions in modelling their experience of stuttering. It supports the view that the nature of PWS' perceptions of their experience can be considered by a multileveled and complex framework. The SRMD framework considers these complexities by focusing the effect of the interaction between personal and social elements that shape a person's experience.

# Chapter 3: A Systematic Literature Review of Research in the Lived Experience of People who Stutter (PWS) and Public Attitudes toward Stuttering

The purpose of this second chapter in the literature review is to provide a synthesis of research relating to the lived experience of PWS and public attitudes toward stuttering. The main objective of the chapter is to investigate how stuttering experiences and public attitudes toward stuttering have been understood and researched. It identifies gaps in knowledge in the field of stuttering, which have informed the research questions and design.

The search was conducted using peer-reviewed journal articles published between 2000 and 2020 in the University of Reading Library, Google Scholar, PsycINFO, and International Bibliography of the Social Sciences (IBSS). This date frame of twenty years was chosen to include a widespread period of 21<sup>st</sup> century research that explored the lived experience of stuttering and public attitudes. Table 3.1 shows the terms that have been used to conduct this literature review; searches were conducted using single and combined terms.

Table 3.1 The Searching Terms That Used to Conduct the Literature Review

Research terms for the lived experience	Research terms searching for research				
of stuttering:	on public attitudes:				
Narrative, storytelling, life story, life history	Public attitudes toward stuttering, listeners,				
of people who stutter* stammer* experience*	parents, teachers, and peers' attitudes toward				
perspective, stuttering, stammering,	stuttering, people who stutter. Public Opinion				
educational experiences, school experiences,	Survey of Human Attributes-Stuttering				
social experiences, lived experience.	(POSHA-S). Attitudes toward stuttering in				
	Arab countries.				

Furthermore, the search was governed by a particular concentration on the two themes of 'Lived Experiences' and 'Public Attitudes', because these are emerging themes within the stuttering research field, although there has been insufficient research assessing PWS' experiences from their personal perspectives (Isaacs & Swartz, 2020a; Al-Shdifat, Maayah, Mayo, & Louis, 2018). Therefore, while reviewing research into the lived experience of stuttering, the aim was to understand PWS' perceptions of the effect of

stuttering on their own lives, although research into public attitudes is beneficial for understanding those elements linked to the social context wherein PWS interact. The inclusion and exclusion criteria are summarised in Table 3.2. These criteria were formulated by Meline, (2006) as a means of guaranteeing that the identified studies are pertinent to fulfilling the systematic literature review's purpose. The included studies fulfil all of the inclusion criteria, while research studies reflecting one or more of the exclusion criteria were omitted.

Table 3.2 Inclusion and Exclusion Criteria Used for Paper Identification

Inclusion	Exclusion						
•	nce of People who Stutter'						
- Peer-reviewed journal research	<ul> <li>Medical research,</li> </ul>						
articles,	- Research about treatment,						
- Research use qualitative methods,	narrative therapy,						
such as interviews, narrative,	- Research interviewed non-PWS,						
storytelling, life story, life history,	- All research that is not about live						
- Research about PWS'	experiences of stuttering,						
perspective,	<ul> <li>Not available in full text,</li> </ul>						
- Research about PWS' life	- Not published in English.						
experience, educational							
experiences, and social							
experiences.							
Theme 2: 'Public Attitudes T	'oward Stuttering and PWS'						
- Peer-reviewed journal research	- Some studies about intervention						
articles,	to change public attitudes were						
- Research about listeners, parents,	excluded,						
teachers, and peers' attitudes	- Not available in full text,						
toward stuttering and PWS,	- Not published in English.						
- Society's views and attitudes							
toward stuttering and PWS,							
<ul> <li>Arab attitudes toward stuttering,</li> </ul>							
- Public Opinion Survey of Human							
Attributes-Stuttering (POSHA-S).							

Notably, the decision to omit non-English language publications was made due to it being difficult to identify which Arabic language research has received peer-review. Moreover, searching the literature on the basis of the Arabic words *ta'at'a* and *taleathum*, which mean stuttering, as well as *muta'at'*, *mutalaeithim* and *mutalaethimun* which mean 'stutterer' and 'stutterers', yielded no pertinent research written in Arabic or that was relevant to the research subject. However, this does not exclude the regional research,

because there has been research undertaken in Arab countries written in English; these were involved in this systematic literature review.

The initial search for the themes yielded 3,220 results for the first theme, in addition to 3,023 for the second theme. Having omitted all research that did not fulfil the inclusion criteria, the sample was reduced to 759 potential research articles for the first theme and 1,190 for the second theme. Subsequently, all titles and abstracts were screened; only 22 research articles were identified as being relevant to the first theme (the lived experiences of PWS) (Appendix A, page 267), while 25 research articles were related to the second theme (public attitudes toward stuttering and PWS) (see Appendix B, page 276).

Once the total number of articles was determined, those that were qualitative studies into the lived experience of people who stutter were evaluated through adopting the Critical Appraisal Skills Programme (CASP) strategy (CASP, 2018). This was in an attempt to minimise the risk of my personal bias while reviewing them. The CASP is a checklist comprising of ten questions (see the CASP Key in Table 3.3) concerning the qualitative studies' quality, to which the answers are either 'Yes', 'No' or 'Cannot Tell', with explanations also presented for the 'No' and 'Cannot Tell' judgements. (Table 3.4 provides an example of this, while the complete evaluation is presented in Appendix C, page 284).

Table 3.3: The Key for Each Question in the CASP Checklist

#### CASP Key:

- 1 Was there a clear statement of the aims of the research?
- 2 Is a qualitative methodology appropriate?
- 3 Was the research design appropriate to address the aims of research?
- 4 Was the recruitment strategy appropriate to the aims of the research?
- 5 Was the data collected in a way that addressed the research issue?
- 6 Has the relationship between researcher and participants been adequately considered?
- 7 Have ethical issues been taken into consideration?
- 8 Was the data analysis sufficiently rigorous?
- 9 Is there a clear statement of findings?
- 10 How valuable is the research? (CASP, 2018)

Table 3.4: An Example of CASP Evaluation

Author(s)	CASP Question									
and Year	1	2	3	4	5	6	7	8	9	10
Nang,	Yes	Yes	Yes	Yes	Yes	Can't	Yes	Yes	Yes	Yes
Hersh,						Tell				
Milton, &						(1)				
Lau,										
(2018).										
(1) No provision of information.										
O'Dwyer,	Yes	Yes	Yes	Yes	Yes	Yes	Can't	Yes	Yes	Yes
Walsh, &							Tell (1)			
Leahy										
(2018)										
(1) No pertinent ethics information could be found.										
Plexico,	Yes	Yes	Yes	Yes	Yes	Can't'	Can't	Yes	Yes	Yes
Manning,						Tell (1)	Tell (2)			
Levitt,										
(2009a) and										
(2009b)										
(1) Researcher subjectivity was covered to a certain extent, although the										
respondents and the researcher's prior relationship was not discussed. Given										

that the researchers had worked with the respondents in previous investigations, there was a particular requirement to explain any relationship.

(2) No discussion of ethics, confidentiality or consent seemed to be provided.

The evaluation of the quantitative studies of public attitudes toward stuttering was assessed according to the methods used to collect the data. Thus, in terms of measuring public attitudes, there has been widespread use of the 'Public Opinion Survey of Human Attributes-Stuttering' (POSHA-S) to measure the beliefs, knowledge, and attitudes of the public toward stuttering (St. Louis et al., 2014; St. Louis, 2011). It can be worth noting that the POSHA-S is a survey that was developed for use across the world (St. Louis, 2005; St. Louis, 2011). It has proven to be a valid and dependable instrument that has been used in 42 countries and translated into 28 different languages, including Arabic (Al-Shdifat et al., 2018). POSHA-S' primary advantage lies in the fact that those who translated it into various languages include people who not only spoke another language but also were from the countries and cultures that spoke the language; thus, ensuring that POSHA-S was implemented appropriately taking into consideration cultural differences (St. Louis et al., 2014). Accordingly, research studies applying POSHA-S as a data collection method were deemed to be appropriate for inclusion in this literature review.

Following their selection, the research articles were reviewed via qualitative Thematic Analysis (Braun & Clarke, 2006). The analysis included the labelling of all significant information associated with the study topic; for example, concepts, theories, methods and results, followed by grouping them into themes and sub-themes in accordance with their meanings. These themes determined the key sections of this systematic literature review. Presenting the literature review using themes offers a flexible strategy for synthesising relevant literature (Green, Johnson, & Adams, 2006), as well as for identifying answers drawing on a range of resources and evidence (Riessman & Quinney, 2005). This approach was adopted as a means of holistically exploring the main data as well as fundamental concepts derived from the research articles (Jones, Gallois, Callan, & Barker, 1999; Ryan & Bernard, 2003). It was particularly appropriate as a choice for this study because Thematic Analysis was also employed to analyse the data collected from the participants in the study. The chapter is in two main parts: firstly, literature related to the lived experiences of people who stutter; and, secondly, literature related to public attitudes toward stuttering and individuals who stutter.

#### 3.1: The Lived Experiences of People who Stutter

The first part of this literature review focuses on the research studies relating to the lived experiences of people who stutter (PWS). To begin, it is instructive to give an overview of these studies, with consideration being given to the methodology used, context and background. Seventeen qualitative research studies were identified that met the inclusion criteria (Appendix A, page 267). These included qualitative research, typically adopting a narrative strategy and focusing on individuals' experiences of stuttering. For example, a semi-structured interview and focus group approaches were adopted in most studies to obtain much of the data from the participants (Connery, McCurtin, & Robinson, 2019). The adoption of these narrative strategies is the principal distinction in the studies. Nevertheless, the decision of what to discuss was made by the subjects only in O'Dwyer, Walsh and Leahy's (2018) research, with one opening request and little questioning during semi-structured interviews. These narrative studies are important because they helped inform the methodological design of this study.

Due to the limited number of qualitative research studies, an additional quantitative and mixed-methods studies were included. The quantitative and mixed-methods studies

comprised of two mixed-method studies (Beilby et al., 2013; Carter, Breen, Yaruss, Beilby, 2017) and five quantitative studies (Plexico Erath, Shores, & Burrus, 2019; Adriaensens, Beyers & Struyf, 2015; Erickson & Block, 2013; Hayhow, Cray, & Enderby, 2002; Kawai, Healey, Nagasawa, Vanryckeghem, 2012). These studies are also important because they can provide a layer of statistical evidence for the common themes related to stuttering experiences, such as avoidance and coping mechanisms.

Little up to date, qualitative research has been conducted with Arab PWS about their experience of stuttering. Thus far, only a part of an article by Alqhaz, Blomgre, & Roy, et al., (2017) discussed Arab (Jordan) PWS. In other studies, various country contexts were explored: for example, the USA (Plexico, Manning & Dilollo, 2005, 2009a, 2009b; Tichenor & Yaruss, 2018), South Africa (Klompas & Ross, 2004; Kathard, Norman, & Pillay, 2010), the UK (Crichton-Smith, 2002; O'Dwyer, Walsh, & Leahy, 2018), and Australia (Bricker-Katz, Lincoln & Cumming, 2013; Beilby et al., 2013) (for more details see Appendix A, page 267). Therefore, this study's focus on the potential influence of some of the social and cultural features of Saudi Arabia on the lived experience of stuttering contributes to bridging this gap in the literature.

There is also a dearth of information concerning the way in which people who stutter relate to their intrapersonal-external interactions. Therefore, in this literature review, a link was made between the Social Relational Model of Disability (SRMD) and stuttering experience, which respects individuals who stutter by considering both internal and external factors that might be relevant to their experiences. The generated themes of this literature review discuss PWS' experience as related to the various aspects of their experience, as opposed to exploring the effect of stuttering on every aspect discretely. The themes were named using sentences that reflect a synthesis of the analysis across the included research studies. Four themes emerged, which are presented in Table 3.5. Following this, the section ends with a summary of the key points.

Table 3.5: The Themes Emerging from Research into the Lived Experiences of Stuttering

- Social and Educational Experience and PWS' Self-Identity and Concept;
- Social and Employment Experience and PWS' Quality of Life;
- The Impact of Stuttering in Social Relationship;
- Avoidance to Cope with Stuttering and Social Barriers;

# 3.1.1: Social and Educational Experience and PWS' Self-Identity and Concept

Several research studies have indicated that a significant relationship exists between PWS' communication difficulties and their perception of self (Nang et al., 2018; Adriaensens, Beyers & Struyf, 2015; Boyle, 2015). Social interactions can be a significant factor causing challenges, which can make PWS feel less positive about themselves. Negative self-perceptions, stemming from childhood or feedback from others can result in the creation of a damaging self-identity and concept (Daniels, Hagstrom, & Gabel, 2006). People's identity, including how they consider their abilities, can be a significant element for PWS' well-being (Carter, Breen, & Beilby, 2019). Low self-identity may impact the individuals who stutter, and it can make it problematic to live with this speech impediment (Daniels & Gabel, 2004). The following paragraphs discuss the influence of social interaction on PWS' self-identity, and the role of educational difficulties in shaping PWS' self-identity.

PWS may reconstruct their self-identity and self-concept as a result of their challenges with social interaction throughout their lives, including during their early childhood and school-age years (Beilby, Byrnes, Meagher, & Yaruss, 2013; Daniels et al., 2006). This can establish the foundation for long-term experience of stuttering (Lee, 2014). PWS might be at risk of facing negative social interactions and negative feedback about their stutter throughout their lives, even prior to being of school-age (Nang et al., 2018). Such social evaluation and adverse reactions can result in PWS formulating negative selfidentity (Kathard et al., 2010). For example, research has evidenced a significant level of pessimism among non-stuttering pre-schoolers towards stuttering (Glover, Louis, & Weidner, 2019; Weidner, St. Louis, Nakisci, & Ozdemir, 2017). Therefore, attitudes and stigmatisation relating to stuttering can become increasingly apparent during interactions with others as part of the experiences of a child who stutters (Boyle, 2013; St. Louis, 2015; Boyle, Dioguardi & Pate, 2016). Thus, a child becomes conscious of the difficulties with their own speech, as well as the reaction of others towards them, when others also recognise the differences between those who do and do not stutter. In turn, children potentially reconstruct their self-concept and identity as 'different', or as 'stutterers' as a consequence of their interactions with others.

In school, children expand their social circle to include educational professionals as well as their peers, and this can also increase the opportunity for adverse feedback (Carter et al., 2019). For example, educational experiences that involve teachers' negative feedback may detrimentally affect PWS' self-identity and concept (García-Pastor & Miller, 2019; Klompas & Ross, 2004). Numerous PWS who participated in research studies reported their feelings about others' discouraging evaluations and feedback, for example when they were bullied at school or received insufficient support (Plexico et al., 2009b; Hayhow et al., 2002), as well as being grouped with low-functioning students, or being returned to a younger grade (Daniels et al., 2012; Hayhow et al., 2002; Klompas & Ross, 2004;). Hence, there is a risk that a stutter might typically result in the perception of those children as having a lower social and academic status, which may ultimately result in bullying and verbal abuse (Yaruss, Murphy, Quesal, & Reardon, 2004; Blood & Blood, 2016; Langevin, 2015). Consequently, stuttering could account for observable reductions in their academic experience (Klompas & Ross, 2004; O'Brian, Jones, Packman, Menzies, & Onslow, 2011).

These negative school experiences can help shape PWS' perception of themselves. For example, some students who stutter perceived themselves as less 'smart' compared with their peers (Adriaensens et al., 2015), potentially reflecting the challenges they confronted with classroom participation. This is because people tend to build and shape their self-identity and produce images of themselves through reflecting on the feedback and reactions they receive from others, including teachers and peers (Bricker-Katz et al., 2013). In this regard, despite stuttering having a greater likelihood of occurring before the age of school (Nippold & Packman, 2012), PWS are more likely to recognise it as being a problem as a result of their difficult experiences at school (O'Dwyer et al., 2018). Nevertheless, very few studies have looked at the effect of stuttering in school on the longevity of stuttering throughout an individual's lifetime (Daniels et al., 2012).

In summary, the evaluation of the literature suggests that PWS can reconstruct their selfidentity via their interpretation of intrapersonal-external interactions. Such interpretation can result in greater recognition of the stutter, which refers to the action when an individual realises that they have a stutter. The following sections present and further discuss themes related to the impact of stuttering on the lived experience of PWS.

#### 3.1.2: Social and Employment Experience and PWS' Quality of Life

The term 'quality of life' has been adopted in research relevant to this study to refer to the challenges that PWS confront in their everyday lives, as well as how PWS react to living with the stutter (Bricker-Katz, Lincoln, & McCabe, 2009). It involves aspects linked to PWS' emotional, educational, professional and social life relationship (Crichton-Smith, 2002; Scharf, 2017; Klompas & Ross, 2004). The effect of stuttering on PWS' quality of life has been researched in several studies (see, for example, Klompas & Ross, 2004; Nang et al., 2018; Crichton-Smith, 2002). The majority of such literature has evidenced that stuttering negatively affects PWS' quality of life. Consequently, an expectation exists that PWS' overall lives will markedly differ from those of other people who do not stutter (Crichton-Smith, 2002; Connery et al., 2019).

Quality of life appears, in some research studies, to be determined by PWS' perceptions and feelings of dis/satisfaction (Plexico et al., 2009a, 2009b; Nang et al., 2018), alongside their self- efficacy (Carter et al., 2017). While other studies have identified that stuttering's negative effect is dependent on the stuttering's severity; the more severe, the more that stuttering will undermine PWS' quality of life (Adriaensens, Beyers, & Struyf, 2015; Craig, Blumgart, & Tran, 2009). Research studies also have identified that a greater frequency of PWS confronts additional life obstacles, including social, emotional and employment issues, resulting in a poorer quality of life (Plexico, Erath, Shores, & Burrus, 2019; Carter, Breen, Yaruss, Beilby, 2017; Beilby et al., 2013; Klompas & Ross 2004). Research such as that undertaken by Plexico et al. (2009a, 2009b), Nang et al. (2018), and Klompas and Ross (2004) has positively contributed to understanding the effect of stuttering on PWS' lives. Such research has presented qualitative evidence concerning PWS' derived meanings from how they feel about the effect of stuttering on their quality of life. More specifically, the social and professional aspects of PWS' life were commonly connected to PWS' perception of their quality of life (McAllister, Collier, & Shepstone, 2012). With regards to the social effect on PWS' quality of life, their feeling of social discrimination and stigmatisation appears to detrimentally affect PWS' life experience (Alqhazo et al., 2017; Walden, Lesner, & Jones, 2020). Alternatively, experiencing positive social inclusion and relationships may enhance PWS' quality of life (Klompas & Ross, 2004).

The second area for consideration includes opportunities for a career or paid work. Employment is a significant component of life and self-satisfaction, which research has suggested is diminished for PWS (Craig, 2010; Yaruss, 2010; Craig, Blumgart, & Tran, 2009). There is a substantial effect on work, for example, opportunities for finding an appropriate job, establishing a solid financial standing and ensuring robust job performance. At the same time, PWS can face an extra financial cost as a result of stuttering (for example, the cost of speech treatments) (Blumgart, Tran, & Craig, 2010). Additionally, certain PWS believe that their life choices, including their jobs, have been affected by others' feedback advising them to take on job roles that do not require verbal skills (Hayhow et al., 2002; Ellis & Hartlep, 2017). Hence, PWS often have additional difficulties impacting the quality of their lives resulting from difficulties in finding jobs (Bricker-Katz, Lincoln, & Cumming, 2013; Nang et al., 2018; Gabel, Blood, Tellis, & Althouse, 2004).

The findings of these studies have highlighted the crucial role of the social and workplace environment in shaping PWS' experience, meaning that PWS may require an encouraging society and workplace environment where stuttering does not affect their promotion and progression (Klompas & Ross, 2004). Ultimately, the fact is that stuttering can severely affect an individual's quality of life, differentiating it from what may be perceived as a person's 'normal' lifestyle. The negative implication which can be beyond communication difficulties is the risk that greater social obstacles and challenges are confronted by those who stutter. According to Connery at al. (2019), this may result in dissatisfaction with their own lives.

Despite the reports of a potentially negative life experience among PWS, other research reports that a stutter's consequences need not be negative, and that the stutter's effect varies in severity across different individuals (Nang et al., 2018; Koedoot, Bouwmans,

Franken, & Stolk, 2011). In fact, most of the literature regarding PWS' quality of life has primarily been concerned with focusing on stuttering's negative effects on people's lives. However, research may overlook other variables that can potentially contribute to people's difficulties. For instance, PWS' lack of self-acceptance and the adoption of avoidance behaviours in social and workplace contexts, all of which can affect their quality of life. Thus, PWS' ability to cope and accept the stutter and the type of coping mechanisms and acceptance or lack of acceptance can shape PWS' lived experience (for example, Plexico et al., 2019; Hayhow et al., 2002; Beilby, Byrnes, Meagher & Yaruss, 2013). Ultimately, there is a requirement for greater understanding relating to how individuals' quality of life is affected by stuttering, or how different variables potentially interrelated to stuttering affect PWS, hence the focus of this research.

#### 3.1.3: The Effect of Stuttering on Social Relationships

In addition to self-concept and work opportunities, several research studies have indicated that stuttering negatively affects PWS' social relationships, including those with family members and friends (Beilby et al., 2013; Alqhazo et al., 2017; Klompas & Ross, 2004). Despite stuttering not being connected to PWS' ability to establish friendships (Daniels, Gabel, & Hughes, 2012; Klompas & Ross, 2004; O'Dwyer et al., 2018), they potentially suffer from having fewer friends since school age and throughout their lives (Nang et al., 2018). This, in turn, can result in PWS' perceptions of their familial and friendship social connections involving negative feelings relating to insufficient social support (Plexico, Manning, & Levitt, 2009b), as a result of their feelings of being disconnected from their families and close friends (Nang et al., 2018). A dearth of social engagement was perceived primarily as negatively affecting PWS' school experiences, particularly their relationships with teachers and peers, to a greater extent than it affected their lives (Daniels, Hagstrom, & Gabel, 2006; Daniels, Gabel, & Hughes, 2012). Research established that having close friends in school may enhance PWS' self-esteem in addition to their overall school experience (Adriaensens, Beyers, & Struyf, 2015). However, limited research has considered PWS' perceptions of their friendships.

Much of the research typically refers to the negative consequences and secondary effects of stuttering as opposed to highlighting the role of speech difficulties during the discussion of the effect on their social relationships (Nang et al., 2019). Stuttering's

secondary effects, for example, avoidance and social anxiety, may be perceived as negatively affecting their social relationships (Crichton-Smith, 2002), alongside PWS' communication attitudes (Blood, Blood, Tellis, & Gabel, 2001). Given that PWS usually perceive themselves as possessing poor communication competence (Blood et al., 2001), they may also face challenges in terms of developing their communication skills. Previous experiences with failing to develop these communicational skills may undermine their social relationships (Erickson & Block, 2013).

PWS' perception of other people's negative reactions in their surroundings may influence the manner in which they feel connected to them. PWS' parental relationships were of interest in Klompas and Ross' (2004) research, where sixteen PWS were interviewed and seven indicated that their stutter had impacted their relationship with their parents. Klompas and Ross' research findings may highlight what PWS deem to effect their parental relationship positively or negatively. The research participants in this study, and in Nang et el.'s (2018) research, perceived the relationship with their parents as negative when they felt there was insufficient understanding of their stutter. PWS' adverse feelings emerge in instances where their stuttering results in their parents feeling bad, when their parents complete their sentences, as well as when they treated them differently from their siblings (Klompas & Ross, 2004). Meanwhile, other participants who stipulated that their stutter did not impact their parental relationships explained that their parents provided them with sufficient support, as well as not treating them any differently than their siblings (Klompas & Ross, 2004). Klompas and Ross (2004) as well as Nang et al.'s (2018) studies are significant for this thesis, given that they involved female participants in the sample. Moreover, they provided rich data on the lived experience of stuttering and when it is considered to be a problem.

Therefore, the relationship between PWS and their parents may simply reflect the manner in which they think their parents were affected by their stuttering. In this regard, families' attitudes towards stuttering are potentially a significant variable contributing to shaping PWS' experience of stuttering and this is reviewed in Part 2 of this chapter. Ultimately, it may be concluded from the literature that an overarching relationship exists between PWS' social lives and stuttering severity, as alongside the secondary effects of stuttering. These secondary impacts pertain to the array of implications of having a stutter, including personal perceptions and the social environments of home and school.

#### 3.1.4: Avoidance to Cope with Stuttering and Social Barriers

Avoidance behaviours (see definition Section 1.3) is perhaps the most common theme that has been predominantly linked to PWS' lived experiences (Isaacs & Swartz, 2020a). PWS adopt various methods for avoidance, for example, avoidance of particular words (Klompas & Ross, 2004) and stressful social situations (Butler, 2013b; Daniels et al., 2006). This section explores avoidance behaviours as a construct with regards to both stuttering and negative social reactions.

Certain PWS adopt avoidance behaviours as a means of hiding their stutter (Carter et al., 2017) and to prevent themselves from being in stressful situations (Plexico et el., 2009a). Indeed, many PWS begin carrying out avoidance behaviours during their childhood (Crichton-Smith, 2002). Such behaviours may influence PWS' attitudes towards communication from an early age. For example, students who stutter were identified as expressing negative attitudes towards communication (Erickson & Block, 2013), while they also usually adopted avoidance behaviours, particularly in terms of averting participation in classroom activities (Kawai, Healey, Nagasawa, & Vanryckeghem, 2012; Daniels et al., 2012). Students who stutter find participating in school activities that require speaking, for example, reading aloud, as particularly stressful (Hayhow et al., 2002; Daniels et al., 2012). Thus, on the one hand when some PWS appear to opt for avoiding commutation as a means of hiding their stutter and avoiding feelings of stress, this type of avoidance is referred to as 'emotion-based avoidance' (Plexico et al., 2009).

PWS may also feel compelled to avoid social interactions because of social and educational barriers such as negative social reactions, or teachers' negative feedback. The fear of negative feedback and evaluations can result in many PWS avoiding communicating with others (Daniels, Hagstrom and Gable, 2006; Ellis & Hartlep, 2017; Bricker-Katz, Lincoln, & Cumming, 2010). Avoidance behaviours, in these cases, may be engaged in by PWS not just to protect themselves from enduring stressful situations, but also to avert others, including teachers and peers, negative evaluations of them (Daniels et al., 2012; Ellis & Hartlep, 2017). Thus, the development of PWS' desire to communicate is elevated through social interactions (Plexico, Manning, & Levitt, 2009a; Carter, Breen, & Beilby, 2019). Negative social interactions may exacerbate the feelings

of discrimination and isolation within the social environment. Subsequently, this produces adverse attitudes towards others in addition to the adoption of social exclusion (Crichton-Smith, 2002; Butler, 2013a). In this case, the avoidance behaviours can become more of a management strategy and comfort as they avert any form of external situation that potentially results in pressure and distress (Kathard, Norman, & Pillay 2010; Carter, Breen, & Beilby, 2019).

On this basis, the onset of avoidance behaviours may be a direct consequence of such exposure to greater negative social attitudes (Crichton-Smith, 2002), as well as stigmatisation (Butler, 2013a). The feeling of deliberate exclusion might arise for PWS from within their own peer group, where they might be socially excluded by others (Langevin, Packman & Onslow, 2009). They may even receive negative comments, akin to bullying or rejection (Davis, Howell, & Cooke, 2002). For example, some students who stutter explained they might even be excluded from classroom activities by their teachers, who may be reluctant to provide longer time for a student who stutters to complete a reading task (Hayhow et al., 2002). As a result, students who have an impression that their teachers and peers will feel discomfort from listening to their stuttering will also potentially adopt avoidance behaviours to eliminate any listeners' discomfort (Plexico et al., 2009a). Although avoidance is used to reduce stress, many PWS perceive avoidance behaviours negatively because of its effect on their social and educational lives (Plexico et al., 2005; Corcoran & Stewart, 1998; Crichton-Smith, 2002). The term 'Avoidance behaviours', therefore, is not only a common theme that PWS discuss while narrating their lived experience of stuttering, it may also result in a profound effect on PWS' quality of life (Carter et al., 2017).

#### 3.1.5: Conclusion

PWS' lived experience of stuttering is an overarching topic that includes complex known and unknown elements. Such elements can shape an individual life, including past experience, social relationship, life choices and achievement, etc. Thus, there is an inherently subjective aspect to the experiences of PWS. Everyone can have his or her unique life experience, and research in PWS should take this into consideration. However, most of the included research studies, both qualitative and quantitative, were designed to

assume the negative impact on PWS. In addition, connecting PWS' lived experiences with others' perspectives and attitudes was not clearly presented in the included research studies. The following section concerns non-stutterers' perspectives and attitudes. It is titled 'public attitudes toward stuttering', which is the term adopted in research studies in this field.

#### 3.2: Part 2: Public Attitudes towards Stuttering

This section presents a critical review of research that has investigated non-PWS' attitudes towards stuttering. Furthermore, it connects this issue to certain social and cultural dynamics affecting PWS' experiences. Additionally, an analysis of further variables underpinning this phenomenon is related to the Saudi Arabian context. Most of the included research studies adopted the Public Opinion Survey of Human Attributes-Stuttering (POSHA-S) for measuring public attitudes towards stuttering (St. Louis, 2011). This section considers and analyses four themes (Table 3.6):

#### Table 3.6: Themes in Public Attitudes towards Stuttering

- Parental Attitudes towards Stuttering;
- Teachers' Attitudes towards Stuttering;
- Children and Peers' Attitudes towards Stuttering;
- Public Attitudes towards stuttering with Regards to Cultural Dynamics.

#### 3.2.1: Parental Attitudes towards Stuttering

Scant research has concentrated on parents' attitudes towards stuttering (Bodur et al., 2019). The most recent research regarding parental attitudes was undertaken by Salehpoor, Latifi, and Tohidast, (2020), Glover, St. Louis, and Weidner, (2019), as well as Bodur et al. (2019). The rationale for researching parental attitudes is to investigate parental knowledge and attitudes towards stuttering and PWS. Most studies into parental attitudes have posited the significance of parents in the treatment and effect of stuttering on their children who stutter (for example, Langevin et al., 2010; Salehpoor et al., 2020; Bodur et al., 2019; Al-Khaledi et al., 2009). The following paragraphs present the main results of the included research focusing on parental attitudes towards stuttering, followed by the significance of parents' attitudes in shaping the lived experiences of their children who stutter.

The stuttering of children may adversely affect their parents. Research shows that parents' attitudes have been compared with other parents of children who do not stutter; parents of children who stutter are typically characterised by negative reactions, for example excessive maternal control and expectations regarding their child's obedience, to a greater degree than parents of children without a stutter (Bodur et al., 2019). Meanwhile, other parents of fluent children expressed more positive attitudes towards stuttering (Glover et al., 2019), despite possessing limited knowledge about the stutter (Safwat & Sheikhany, 2014; Al-Khaledi et al., 2009). Salehpoor et al.'s (2020) research concentrated on evaluating parents' cognitive, behavioural and emotional reactions. Parents' cognitive reactions include their comprehension of stuttering's causes, its severity, its symptoms, as well as its treatments (Humeniuk, & Tarkowski, 2016). Behavioural reactions may be verbal or nonverbal responses to their children's stutter, for example eye contact, correction and myriad other types of attention paid to the stutter (Humeniuk, & Tarkowski, 2016; Langevin et al., 2010). Parents' emotional reactions include their negative feelings, for instance sadness, stress and anger (Langevin et al., 2010).

Salehpoor et al. (2020) identified some differences between mothers' and fathers' reactions towards their stuttering children, with mothers expressing stronger emotional reactions compared with fathers. Furthermore, they evidenced that differences in parents' reactions to their stuttering children are dependent on their children's gender: parents of girls who stutter expressed higher (severer) cognitive, behavioural reactions and emotional reactions. Nevertheless, insufficient information was furnished by Salehpoor et al (2020) concerning parents' rationale for these varied reactions, thus making it challenging to practically appraise their findings.

Parental attitudes and the interactions between parents and their children who stutter have a bidirectional effect (Safwat & Sheikhany, 2014). As Al-Khaledi et al. (2009) explained, the manner in which children who stutter react to their stuttering reflects their parents' reactions to their stutter; the more negative their parents' reactions are, the more negative reactions that PWS adopt. Subsequently, this may exacerbate the stuttering's severity (Al-Khaledi et al., 2009). Such research studies indicate that parents' responses were perceived as affecting the reactions of their stuttering children; parents' inappropriate reactions tend to exacerbate children's reactions (Bodur et al., 2019). The effect of parental attitudes towards stuttering are considered as fundamental to stuttering's

exacerbation or diminishment, alongside the level of assistance for children with developing positive self-perception attitudes and perception of their stuttering (Al-Khaledi et al. 2009).

Parents' attitudes concerning stuttering are essential for enabling their children to develop healthy attitudes and communication skills (Safwat & Sheikhany, 2014; Lee, 2014). According to Erickson and Block (2013) and Bodur et al (2019), parental attitudes towards stuttering, their children who stutter, in addition to the upbringing methods, may form the children's stuttering experience and attitudes. Such influence may have a lifelong effect on PWS (Glover et al., 2019). For instance, as children typically learn to talk from their parents, if their parents lack the requisite knowledge for supporting their children who stutter, it is possible that their stutter will develop during early childhood and potentially become difficult to recover from or stop (Nang, Hersh, Milton, & Lau, 2018; Erickson & Block, 2013). Therefore, certain parents appear to be cognisant of the hazards of drawing attention to their children's challenges, while they avoid providing excessive additional care for their children who stutter (Adriaensens et al., 2015). In conclusion, parental attitudes towards stuttering may contribute significantly to informing their children's personal attitudes and lived experience of stuttering.

#### 3.2.2: Teachers' Attitudes towards Stuttering

Teachers' attitudes are especially significant in terms of PWS' lived experiences. Few studies have concentrated on teachers' attitudes, awareness and knowledge of stuttering (Kumar & Varghese, 2018). Studies concerned with investigating teachers' attitudes established that educators are often misinformed about aspects of stuttering knowledge, for example stuttering's causes, while also expressing negative attitudes, for instance stereotyping towards PWS (for example Abrahams, Harty, St. Louis, Thabane, & Kathard, 2016; Abdalla & St. Louis, 2012). Teachers' negative attitudes and stereotypes of PWS, alongside their insufficient awareness regarding stuttering, is crucial and may affect students who stutter in terms of their personal and school experiences (Abdalla & St. Louis, 2014, 2012; Adriaensens & Struyf, 2016). Moreover, educators' attitudes may shape non-stuttering students' activities in terms of their relationship to learners who do stutter (Jenkins, 2010).

Research findings about teachers' attitudes towards stuttering reveals some interesting differences. Although Indian teachers achieved average to positive scores concerning teachers' attitudes and awareness of stuttering (Kumar & Varghese, 2018; Pachigar, Stansfield, & Goldbart, 2011), American teachers were perceived as holding more positive attitudes than Arab teachers in Irani, Abdalla and Gabel's (2012) study. They compared 83 American and 83 Arab (Kuwaiti) teachers, with both sets of teachers expressing affirmative attitudes, although the American educators held more positive attitudes in relation to certain items of the Semantic Differential (SD) scale. These related to 'strong character—weak character', 'unemployable', or 'shy'. Teachers' negative attitudes may be considered to be a consequence of wrong stereotypical beliefs and attitudes regarding PWS, who are regularly described as being anxious, frustrated, shy, quiet, introverted and nervous, while their stuttering is frequently assumed to have an emotional or psychological cause, as in Abdalla & St. Louis' (2012) findings concerning Kuwait, as well as Lee (2014) in Korea.

Abdalla and St. Louis (2012) investigated stereotypes in Arab countries towards PWS, with an emphasis on Arab teachers' attitudes to students who stuttered and these educators' adopted strategies for coping with these students in their classrooms. They established that despite the majority of teachers interviewed being sensitive towards students who stuttered, they were misinformed regarding the reasons behind their stuttering and expressed stereotypical beliefs. Such negative stereotyping among Kuwaiti teachers in Abdalla and St. Louis (2012) research, as well as the Korean teachers in Ahn (2013) and Lee's (2013) studies, were also due to them conveying negative attitudes to questions about PWS' personal and social skills, in addition to their employability. Despite Abdalla and St. Louis' (2012) study being undertaken in Kuwait, similarities in the culture, society and educational system of Kuwait and Saudi Arabia are evident. Accordingly, Saudi Arabian teachers may hold similar attitudes and stereotyping regarding students who stutter, while also possessing equivalent knowledge concerning how these students should be dealt with.

Compared with US educators, less positive attitudes among Arab educators may be for several reasons. One is that greater experience with PWS held by US educators, who participated in Irani, Abdalla and Gabel's (2012) research, with 88% were educating PWS and 77% having previously done so. Contrastingly, the dearth of experience among Arab

educators was indicated by the fact just 27% were teaching PWS (Irani, Abdalla, & Gabel, 2012). Furthermore, informed understanding of communication disorders, in addition to their reasons and possible interventions in an academic context, was possessed by fewer than 10% of Arab educators, indicating the necessity for them to expand their stuttering understanding and knowledge (Abdalla & St. Louis, 2012).

Consequently, it is notable that certain researchers have considered it imperative to strengthen educators' information and proficiency; for instance, through improving teachers' professional development to support students with a stutter (Gottwald & Hall, 2003; Klompas & Ross, 2004; Jenkins, 2010). Nevertheless, and significantly, the study explored whether educators are sufficiently prepared to manage students who stutter or not. For example, Indian teachers participating in Pachigar, Stansfield, and Goldbart's (2011) research largely had no formal training about stuttering, yet still indicated positive attitudes towards supporting students who stutter. Generally, teachers adopted methods for supporting PWS were shaped by their personal beliefs about what they deemed supportive. Adriaensens and Struyf (2016), observed that teachers believed that they may facilitate the diminishment of students' stuttering by not focusing or highlighting it, thus avoiding discussing it. Meanwhile, other teachers deem that their assertion that a young learners' conduct becomes more relaxed is linked to their improved fluency, which shows that achieving greater speech fluency through putting students at ease is substantially advocated among many educators (Kumar & Varghese, 2018). Adriaensens and Struyf (2016) advocated teachers' discussion with students, to identify learners' preferred ways in which educators can support them.

It is also apparent that teachers' attitudes may alter over time; for example, this was reflected in a positive change among American teachers (Irani & Gabel, 2008). Irani and Gabel (2008) noted an improvement in US school educators' attitudes towards PWS in contrast with older studies, such as Clauson and Kopatic (1975), Woods (1975), Yeakle and Cooper (1986), as well as Lass et al. (1992). Irani and Gabel (2008) evidenced that teachers in the US are beginning to develop more positive attitudes over time, alongside accurate knowledge regarding stuttering. Therefore, more recent research into Arab teachers' attitudes is necessary to investigate potential improvements in Arab teachers' attitudes.

To summarise, several findings have been identified from critically analysing existing literature concerning teachers' perspectives and attitudes towards learners who stutter. Firstly, educators' existing knowledge and their attitudes were stressed as linked, with the pedagogical process acknowledged as fundamentally influenced by them, in the majority of extant research. Secondly, learners who stutter were generally perceived negatively by educators, who had minimal understanding of the condition. Thirdly, ambiguity was apparent regarding the degree to which learners' social communication and academic attainment are detrimentally affected by educators' knowledge and attitude problems. Fourthly, educators' positive attitudes towards learners who stutter were more apparent in research undertaken within the past years, although teachers considered such learners to be meek, non-verbal, anxious, insecure and introverted in the majority of extant research.

#### 3.2.3: Children and Peers' Attitudes towards Stuttering

Despite attitudes and reactions of non-stuttering children and school peers potentially being a significant aspect of PWS' lived experiences, limited research has concentrated on investigating children and school peers' attitudes towards stuttering and PWS (Weidner, St. Louis, & Glover, 2018). While discussing children's attitudes, certain studies have focused on whether children can recognise the differences in speech of children who stutter, indicating that despite children possibly not knowing the name 'stuttering' at their age, they can nevertheless distinguish between fluent and stuttering speech (Weidner, St. Louis, & Glover, 2018). Given that children can identify stuttering as different, it may be meaningful to assess how they react to stuttering.

Studies have compared children's attitudes with parents and teachers' attitudes towards stuttering. Among these, research has evidenced that children possess more negative attitudes towards stuttering in contrast with their parents or teachers (Glover, St. Louis, & Weidner, 2019; Weidner, St. Louis, Nakisci, Ozdemir, 2017). St. Louis, Weidner, and Mancini (2016) included a sample of 38 child–parent sets, noting that the attitude scores of pre-schoolers on the POSHA–S/ Child were significantly less compared with those of their parents on the POSHA–S. Although this research provides preliminary findings suggesting that young children's attitudes are not affected by their parents, children's attitudes towards stuttering may alter and improve as they mature (Glover et al., 2019;

Özdemir, St. Louis, & Topbaş, 2011). This may be deemed a normal learning process because they adopt improved social skills for respecting others. Meanwhile, children's negative attitudes may stem from their insufficient awareness of stuttering and how they should react to it (Weidner, St. Louis, et al., 2015).

Other researchers have identified certain challenges which students with a stutter confront as a result of their non-PWS peers' adverse social attitudes. For example, PWS may face rejection from their peers (Walden & Lesner, 2018; Evans, Healey, Kawai, & Rowland, 2008; Davis, Howell, & Cooke, 2002). Additionally, research studies have evidenced that children's harmful attitudes may be represented by mistreatment, bullying, teasing, tormenting, and showing visible confusion (for instance Langevin et al., 2009; Abdalla & St. Louis, 2014; Klompas & Ross, 2004). Non-stuttering students' adverse attitudes may comprise their beliefs and perceptions of students who stutter, potentially viewing them as more vulnerable, less able and less assertive (Walden & Lesner, 2018). For example, pre-schoolers typically perceived a child who stutters as 'unable to speak well' and 'different' (Glover, St. Louis, & Weidner, 2019).

Gender possibly plays a role in school peers' attitudes, as observed by Blood and Blood (2004). Despite both boys and girls who stutter potentially being bullied, compared to girls there is a higher probability of boys experiencing direct bullying, such as threats and getting physically assaulted, which may affect their self-esteem and result in them avoiding communication. Hussein (2010) compared bullying in the US and Saudi Arabia, establishing that in comparison to the US, bullying of children who stutter is more prevalent in Saudi Arabia's schools. Their study also compared bullying in boys' and girls' schools, noting that more bullying occurs in the former. Thus, it may be considered that there is a greater risk of boys with stuttering and their peers in Saudi Arabia developing negative relationships. Regardless, it must be observed that a degree of divergence in social norms is apparent between the USA and Saudi Arabia, which could affect what the respective societies deem to be bullying, and might limit the value of Hussein's research. Schools in Saudi Arabia are single sex, while the majority of US schools are mixed sex. Accordingly, the results may be affected by both the gender of the schools' accepted pupils and the context.

In summary, research into children and peers' attitudes towards stuttering has concentrated on investigating two main aspects. The first aspect concerns whether or not non-stuttering children are able to recognise stuttering speech, with it being established that children are able to distinguish stuttering from fluent speech. Secondly, research has explored children and peers' negative attitudes and reactions to stuttering. Regarding children' attitudes, studies have identified that children can express negative attitudes and engage in reactions such as bullying. Furthermore, children's attitudes were compared with their parents and teachers, with research evidencing that children hold more negative attitudes compared with their parents and teachers (Weidner et al., 2017; Glover et al., 2019).

#### 3.2.4: Public Attitudes towards Stuttering as Related to Culture

Societal attitudes towards stuttering and PWS can be fundamental to PWS' formation of their lived experiences (Glover et al., 2019). Social attitudes and knowledge regarding stuttering may be culturally engrained throughout people's interactions (Glover et al., 2019). Recently, an increasing volume of research studies have been evaluating stuttering within various countries and cultures (for instance St. Louis et al., 2016; St. Louis & Roberts, 2010; St. Louis, 2005), as a means of observing similarities as well as differences concerning public attitudes towards stuttering and PWS (St. Louis et al., 2014). These research studies (St. Louis & Roberts, 2010; St. Louis et al., 2005) evidenced that public attitudes towards stuttering may be shaped by culture. The majority of research studies have typically contrasted public attitudes in a country case study to public attitudes in western countries as established through other research studies. Therefore, this section has shed some light on certain comparisons between Western studies and research conducted in the Middle East, where Saudi Arabia is located.

Studies have evidenced that, in contrast with people from Middle Eastern countries, those from Western countries typically express more affirmative attitudes (see St. Louis, Williams, Ware, Guendouzi, & Reichel, 2014). Research adopted the POSHA-S survey for analysing attitudes in Western countries, for example in North America, Western Europe, as well as Australia, with more average to positive attitudes found towards stuttering and PWS (for example St Louis et al., 2014; Przepiorka, Blachnio, St. Louis, & Wozniak, 2013). Positive attitudes revealed in such investigations have established

that individuals may possess a degree of knowledge about stuttering, for example its causes. Nevertheless, despite people holding more positive attitudes towards stuttering in Western counties, certain negative feelings may still arise, such as feeling uncomfortable while talking to PWS (Przepiorka et al., 2013). Alongside these, negative stereotypes exist regarding stuttering, for example that PWS are more anxious, weak, or less capable compared with individuals who do not stutter (Boyle, Daniels, Hughes, & Buhr, 2016).

Despite studies showing that attitudes in western countries are more positive towards stuttering compared with Middle Eastern counties, one exception is Kuwait where studies find there are more affirmative attitudes towards stuttering (Al-Khaledi et al., 2009). Furthermore, studies concerning attitudes in Saudi Arabia and Kuwait observed certain similarities regarding public attitudes toward stuttering (Al-Khaledi et al., 2009; Abdalla & St. Louis, 2012, 2014). Regardless, these researchers observed that despite there being positive attitudes to a certain extent among Arabs in Kuwait and Saudi Arabia with regards to stuttering, it is crucial to enhance both their public knowledge and awareness (Al-Khaledi et al., 2009; Abdalla & St. Louis, 2012, 2014). Hence, people's positive attitudes may not necessarily produce a positive effect on those PWS, given that the term 'positive' in public attitudes studies does not clarify what is considered as positive or negative attitudes by those who stutter.

For example, the POSHA-S survey's distance and sympathy dimension was negative when undertaken with some Arab people (Alshdifat, Mayo, & St. Louis, 2013; Al-Khaledi et al., 2009; Abdalla & St. Louis, 2012, 2014). Considering sympathy as either negative or positive is in fact questionable. Sometimes it may be deemed as being positive (Hasnain, Cohon, & Shanawani, 2008), because some individuals express sympathy with PWS due to the realisation that they are not to blame if they are unable to control it. However, sympathy can also be a negative attitude; sympathy might also be construed as the perception that individuals with a stutter are somehow 'less' than others without a stutter, with an emphasis placed on their weaknesses as opposed to their strengths (St. Louis, 2011). Therefore, more studies are needed to investigate the meanings and factors informing the differing attitudes among people from various countries. Moreover, when comparing attitudes internationally, there is a need to understand people's meanings in terms of their responses and behaviours, so as to understand whether people are holding negative or positive attitudes. Although POSHA-S is pervasively accepted as a means of

measuring public attitudes, the limitation of surveys including POSHA-S is the dearth of meaning in relation to the findings with regards to how they are relevant to individuals.

#### 3.3: Conclusion

This systematic literature review has presented the research into the lived experience of stuttering and public attitudes, with a number of gaps being identified in this literature: the lived experience of stuttering was not connected to the individuals' context; research into public attitudes did not mention the effect on PWS personally; no research in the context of Saudi Arabia, as well as limited research studies including females who stutter.

Generally, research into public attitudes and stuttering experiences has emphasised the significance of harmful stereotyping, with stuttering's detrimental outcomes for PWS given prominence in the majority of research studies. PWS' negative experiences are focused on throughout the data collection and discussion aspects of a substantial volume of studies. Accordingly, in order to permit both negative and affirmative dynamics of PWS' overall stuttering experiences to be explicated by them personally, research methods should be characterised by greater flexibility. Ultimately, the methods of assisting and enhancing PWS' experiences when they confront adverse effects could be revealed if PWS' positive experiences are investigated.

Stuttering's effect has been researched largely without exploring individuals' personal meaning making of their experience, as well as how it is connected to their contexts. Consequently, this study used the life stories method as a means of understanding variations in PWS' experiences, in addition to what potential narratives reformulated PWS' comprehension of their stuttering experiences. Furthermore, interpretation of PWS' life stories using the SRMD's framework aims to connect PWS' lived experiences with their personal and social contexts.

Studies focusing on public attitudes have not mentioned the effect on PWS themselves. In order to contribute to filling this research gap, how public attitudes towards PWS and stuttering are understood by PWS themselves was assessed during this study, even if societal attitudes regarding stuttering remained unquantified. The aim is to assess and understand the extent of PWS' comprehension of how their stuttering experiences are affected by public attitudes.

Moreover, insufficient research concerning societal attitudes regarding stuttering has been undertaken in the context of Saudi Arabia, indeed in Arab states more generally, as the literature review here has evidenced. This means that further research is required. PWS' perception of Saudi Arabian societal attitudes towards stuttering as well as PWS was the narrower focus of this study. However, this also contributes to resolving a significant shortcoming in the extant literature, namely the insufficient focus on women who stutter, with both males and females included in this research.

# **Chapter 4: Methodology**

#### 4.1: Overview

This chapter explains the research design and methodology, which has been adopted in order to answer the research questions, and achieve its aims and objectives.

## **4.1.1: Research Questions (RQ)**

RQ1. How do PWS perceive their lived experience of stuttering?

RQ2. What type of narrative do PWS adopt when reconstructing their life stories?

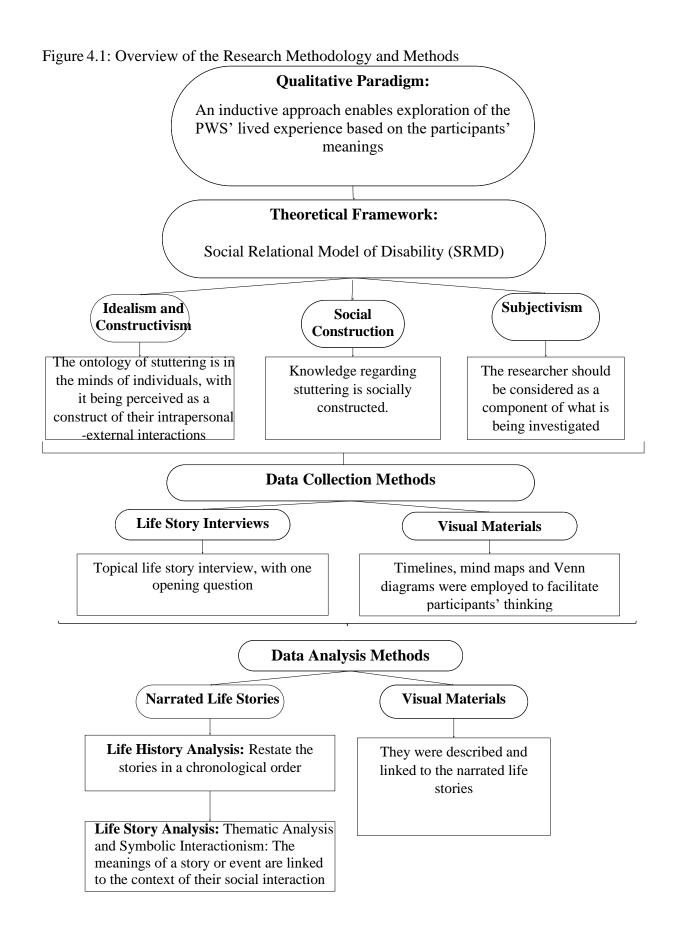
RQ3. To what extent can the Social Relational Model of Disability (SRMD) conceptualise the elements that shape PWS' expression of their life story with stuttering?

#### 4.1.2: Aims and Objectives

- 1) To elicit PWS' voices regarding their experiences through adopting the narrative life story method, alongside collection of visuals materials.
- 2) To connect the SRMD with issues related to PWS' lived experiences.
- 3) To devise a framework offering tangible and practical proposals for the improvement of PWS' social, academic and professional experiences and well-being.

#### 4.1.3: The Research Design

This research adopted a life story approach as a method of data collection and analysis (Rosenthal, 1993). Figure 4.1 (in the following page) provides a summary of the research theoretical position, research approach, as well as data collection and analysis methods selected for this study, which are explained throughout this chapter.



This chapter presents the following aspects of the research method. Firstly, the research's theoretical positionality is clarified, including the ontology, epistemology and axiology. Next the qualitative research design is explained, including the data collection methods and life story analysis method, following which the pilot study is presented. The chapter closes by addressing the issues connected to research integrity, trustworthiness and ethics, as well as a summary.

#### 4.2: Theoretical Positionality

The research's theoretical framework was devised on the foundation of the Social Relational Model of Disability (SRMD) as well as Symbolic Interactionism. The SRMD stipulates that PWS' experiences are connected to their intrapersonal-external interactions (Chapter Two presents a more in-depth explanation of the SRMD, Section 2.2). Furthermore, this study considers Barnes' work (Barnes, Oliver, & Barton, 2002; Thomas, Hatton, Graham, Atkin, & Berghs, 2016), specifically the suggestion that disability research should highlight those external factors that affect those who are deemed to be or deem themselves impaired. Thus, theories of social determinism and domination (Howell, 2013; Guba & Lincoln, 1994) are particularly pertinent to this investigation, because they consider 'stuttering' and related experiences to be an outcome of individual's social interactions and power relations.

Additionally, the application of the Symbolic Interactionism approach underpinned the understanding of the subject under investigation in this research, namely PWS' lived experiences. Symbolic Interactionism has been previously implemented as a means of analysing the participants' life stories and adopted symbols in order to create meanings of various phenomena, including themselves and one another, in addition to their experiences (Plummer, 1990). Such symbols and meanings are deemed to be a consequence of the participant's interpretation of their social interactions (Blumer, 1990; Ball & Goodson, 2005). Accordingly, the SRMD and Symbolic Interactionism are related to this study's ontological and epistemological perspectives, because they are related to knowledge creation and how we know what we know. Ontology, epistemology and axiology, are discussed further below.

## 4.2.1: Ontology of Stuttering Experience

Ontology is a treatment of the reality of being (Saunders, Lewis, & Thornhill, 2009). This section is concerned with the question of what the reality of the stuttering experience is. As explicated via analysing stuttering definitions in the preceding chapters, the nature of stuttering as a condition is complex and multifarious (Hertsberg & Zebrowski, 2016). Stuttering has a social dynamic, given that it typically arises during social interactions (Erickson & Block, 2013; Kathard, 2009). Moreover, it has intrapersonal aspects concerning how PWS interact and respond to social aspects (O'Dwyer, Irene, & Walsh, 2018). The understanding and interpretation of individuals' interactions in relation to these social aspects occurs within people's minds (Gergen & Gergen, 2000). Figure 4.2 clarifies the stuttering experience ontology as used in this study.

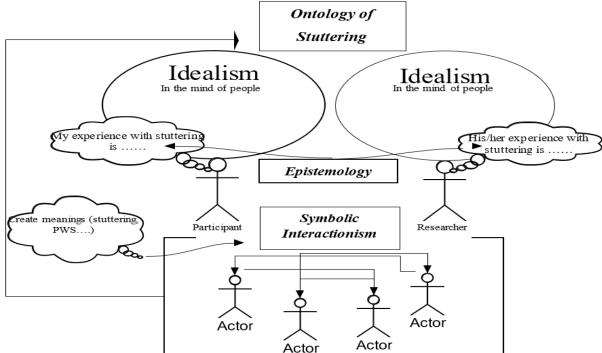


Figure 4.2: Ontology and Epistemology of Stuttering Experience

The Ontology of stuttering experience is formulated on the basis of intrapersonal-external interactions and it is understood through people's thoughts, we as individuals are residing within our own realities (Biggs & Hinton-Bayre, 2008). Accordingly, PWS' biographies related to their lived experience can be appraised from the idealistic perspective (Harrison, 2014). The rationale for emphasising idealism rather than materialism is that

it is impossible to see or touch the stuttering experience, due to it being unmeasurable. For example, the ontology of feelings, emotions and memories in the life story primarily reside in people's minds (Takeda et al., 2019). Theoretically, without human cognition, the stuttering experience may not exist.

Thus, the participants' stories are real to them as evidenced in their personal contexts (Krummenacher & Strang, 2007); each story that they convey is situated somewhere in their minds (McAdams, 2013) and exists there, being linked to their broader intrapersonal-external interactions (Goodson & Sikes, 2001; O'Dwyer, Walsh, & Leahy, 2018). Concerning PWS, their stories may represent particular aspects of their experience, knowledge, and meanings, which is potentially connected to how they perceive (or desire to perceive) their stuttering experience reality (O'Dwyer et al., 2018). In this manner, non-PWS (including myself) have the capability to imagine PWS's stories, appraising them and retaining them within their own memory, possibly associating them with their own personal narratives and experiences, which they may even retell to other people at a later date. Essentially, these stories exist in people's minds as a construction of lived social realities (Watson, 2009), irrespective of whether they are indeed their personal experiences or simply a result of their own cognitive processes, including their thoughts, memories and understanding. In this regard, human minds are a fundamental component of understanding their social experiences and interactions.

With this understanding, it may be significant to remain cognisant that the collected life story interview data may not convey the 'exact' life as lived, rather it potentially emphasises the subjects that participants evaluated as meaningful and pertinent at the specific time of the interview (Bruner, 1986; Etherington, 2009). On this basis, when participants discuss their stuttering life experiences, this becomes authentic knowledge in the context of this study. Subsequently, such experiences may be helpful to widen knowledge within the PWS' experience research field.

# **4.2.2: Epistemology**

Epistemology is concerned with knowledge acquisition (Gordon, 2009), in this context meaning: how do we know the stuttering experience? Symbolic Interactionism approaches to epistemology have previously scrutinised social responses to

environmental interaction (Howell, 2013; Mertens, 2005; Cohen, Manion, & Morrison, 2007) (see epistemology in Figure 4.2 above). Based on the social constructionism and social constructivism perspective, knowledge is deemed as being socially constructed (Gergen & Gergen, 2008). Social constructionism concerns the role of interpersonal engagement in constructing an individual's understanding of themselves and their environment, while social constructivism considers the intrapersonal aspects of such interactions (O'Dwyer, Walsh, & Leahy, 2018). Both perspectives hold the self as being social relational and co-constructed (Neimeyer, 2002).

The epistemology of the stuttering experience may be deemed as a construct of the social actors through Symbolic Interactionism. Symbolic Interactionism concerns people's everyday social interactions that result in creating meanings (Denzin, 1992). Therefore, PWS' self-knowledge and their experiences as stutterers, in addition to non-stutterers' (including myself) knowledge or expectations of PWS' experiences, has a likelihood of having been built via social interactions. PWS' self-narrative and self-emotional interactions are significant, including what people tell themselves about themselves and their experiences (Gergen & Gergen, 2008). Similarly, non-stutterers could construe this as meaning an experience which a PWS has lived through, which may be understood in accordance with their personal observations or discussions with PWS, stemming from the nature of the social interactions arising throughout the research process (Robson, 2002).

In this regard, my interaction with the participants will involve learning (knowledge) through dialogue (the dialogical approach), using oral and/or written methods (Kathard, 2009; Lit & Shek, 2002). People use language-based symbols predominantly as a means of clarifying one another's perspective or point of view. Thus, they have the capacity to arrive at shared meanings, which affects how a particular subject is interpreted by an individual and their understanding of it is defined (Plummer, 1990). For this research, this could have a concomitant effect on the way in which I understand and interpret participants' responses, which subsequently can influence the data on which the study outcomes are based. Consequently, I am cognisant of the research process' subjective significance; I acknowledge that my role is one of facilitation, because participants desire to be heard and understood. On this basis, the qualitative method of 'life story' was selected, so that production and sharing of meaningful narratives is promoted in the context of PWS' experience of stuttering.

### 4.2.3: Axiology: Researcher Positionality

Exploring the values derived from a researcher's personal position, beliefs and attitudes, axiology enables the researcher's positionality to be scrutinised as a variable (Saunders, Lewis, & Thornhill, 2012). As explained during the research ontology and epistemology sections, the researcher's positionality needs to be considered as an aspect of what is being investigated; indeed, it is not possible for researchers to totally distinguish themselves from the research process, therefore introducing some level of subjectivity. Given my direct involvement in determining the research subject, designing the research and identifying an appropriate methodology, one might argue that their subjectivity is inherent (Harrison, 2014). Ultimately, I accept that it may be true that my interpretation of the research data is also influenced by my personal context, based on Symbolic Interactionism, which admittedly could influence the research outcomes (see Figure 4.2 above, Section 4.2.1). Nevertheless, by adopting the life story method, alongside engaging the participants in interpreting their stories, this can help to mitigate my influence on the collected data.

Essentially, acknowledging my subjectivity and my position as knowledge-creators is valuable, given that this can represent an aspect of social interaction as associated with the concepts of the SRMD and Symbolic Interactionism. Through these concepts, interactions are deemed as having responsibility for shared meanings' construction and reconstruction; every individual comprises an aspect of such interactions, that inform the process of creating social values and knowledge (Laird, 1993). Furthermore, my role in interpreting participants' emotions is significant, given that, for example, there is a dearth of existing research tools that are able to effectively measure people's descriptions of their feelings (Alm, 2004). Instead, such descriptions potentially necessitate human interpretation. Therefore, it is essential that I consider myself to be an active participant in the research procedure. Accordingly, I regard myself as positioned subjectively within the research; by employing the SRMD and Symbolic Interactionism, which are interpretive models, an emphasis has been placed on the relationships between interpretation and the phenomena of interest (Howell, 2013). Social phenomena may only be understood through investigation of the ways in which individuals make sense of their surroundings (Ernest, 1994; Mack, 2010). However, no research can be free of its investigator's personal values, because even quantitative researchers are liable to reflect on their research's values in relation to every research dynamic, from selecting words to framing the statement (Gergen, 1999).

A further aspect pertaining to my position is that I am a female of Saudi Arabian nationality. This posits me as an 'insider' in relation to the research participants, given our shared social and cultural background (Asselin, 2003). Yet, Asselin (2003) explained that being a member of a research population does not automatically make myself knowledgeable regarding all sub-cultures, namely the elements of society and culture within the population's context, for example in particular families. However, this position potentially generates social and cultural biases. Therefore, I ensured that I remained sensitive to my position as a female within Saudi society, avoiding the projection of my personal experiences on to the research. Additionally, I needed to ensure that I did not limit male participation, with both females and males comprising the research participants and being treated equally. Being based in the UK during the research played a role in developing my abilities to socially interact with various people.

In addition, although I am specialised in speech and language difficulties, I do not stutter, and it has been suggested by certain academics that research into disabling conditions should only be undertaken by a researcher who has the disabling condition of interest. This could be deemed a conflict as I do not have a parity of experience which could help restrict the potential for analytical misunderstandings (Branfield, 1998), especially when an over- or under-emphasis is of concern (Abberley, 1987). Nevertheless, I consider there to be no benefit from labelling researchers and/or stutterers as 'abled' and 'disabled', particularly due to 'disability' being a matter concerning all humans, both with and without impairments (Shakespeare & Watson, 2002). Also, this study was designed to elicit individuals' voices by engaging them in topical life story interviews, which started with one open question about their life stories, in addition to involving them partly in the data interpretation. Thus, my role was only to facilitate their participation and not to structure the interviews by asking a number of prepared questions. This study aimed to empower the participants by enabling them to recall, recount and review their lives (Booth & Booth, 2005), supporting a co-construction of the research carried out by the participants and myself. This is because that PWS's voice is fundamental to the values for this study, which in turn can fill the gap in the research (Connery et al., 2019). Furthermore, a pilot study (Section 4.7), comprising of a Skype interview, was devised to assess the research methodology, with potential biases screened and determination of the interview topic's level of clarity and acceptability being undertaken.

### 4.3: Qualitative Research Methods

This research necessitated the life story method as a qualitative research strategy (Rosenthal, 1993; Harrison, 2014), enabling PWS to share their perspectives regarding their lived experiences (Creswell, 2013). This qualitative design was employed as a means of understanding individuals' experiences, attempting to reveal and clarify a phenomenon, process, or perspective of the people involved (Caelli, Ray & Mill, 2003). This includes investigating people's subjective perspectives, opinions, emotions, feelings and thoughts on their real-world experiences (Percy, Kostere, & Kostere, 2015; Strauss & Corbin, 1990). The qualitative approach adopted here provided flexibility and was more unstructured (Brannen, 2004), thus aiming to provide greater space for participants to offer and explore in-depth details concerning the subject under investigation (Hunter, 2010). Ultimately, this offers greater opportunity for PWS to freely reconstruct their thoughts relating to their life stories, without being constructed by the research procedure or specific direct questions, as is possibly the situation during quantitative research (Ball & Goodson, 2005).

This research's fundamental focus was on the meanings that individuals ascribed to their stuttering experience. Qualitative research may provide a greater level of in-depth analysis through interpretation of results, including investigation of meanings, interpretations, symbols, processes and relations that shape social life (Saldaña, 2013). On this basis, the research assumption regarding the SRMD's effect on PWS' experience, alongside the life story method, necessitates humans' interpretation of people's 'meaning', which has been constructed via their social and cultural interactions (Hunter, 2010). Moreover, the decision to undertake qualitative research was appropriate for this study with regards to resolving an existing research gap, namely the requirement for a greater amount of qualitative research aiming to explore the meaningful dynamics of PWS' stuttering experiences (Nang, Hersh, Milton, & Lau, 2018).

### 4.4: Participant Selection

Recruitment was based on combining opportunity sampling (Brady, 2006) and purposive sampling, which 'builds in certain characteristics or criteria which help to develop and test the research theory or argument' (Mason, 2002, p.124). A public advertisement was distributed via Twitter and Snapchat as a means of recruiting participants. Ethical principles were considered at this stage by explaining that the research topic of interest was about PWS' life stories, and participating in this study may not have any benefit for treating the stutter (additional ethical considerations are detailed in Section 4.9). Ultimately, 16 participants who were willing to participate made contact regarding sharing their life stories for the academic research.

For this study, the population of interest was female and male Saudi Arabian adults who stutter, aged eighteen and over. The research objective was to investigate PWS' lived experiences of stuttering throughout their childhood, adolescence, adulthood and into the current period. Both genders were included with the aim of addressing a literature gap, namely the present dearth of research into females' experiences with stuttering (Nang et al., 2018). Limiting this research to concentrating on Saudi Arabia was necessary as a means of connecting the generated data to social constructionism and social constructivism's effects on PWS, in connection to their narrower societal contexts. Narrower social contexts include the domestic environment, school and street, alongside broader Saudi Arabian society and culture.

Given the nature of stuttering as a personal issue, it might have proven challenging to reach a substantial number of people with a willingness to participate. However, the study's focus is on data quality as opposed to quantity. Quality may be dependent on participants' willingness to share their experience, alongside the interviewing researcher's competence. The following provides an overview of the participant sample (Table 4.3). The sixteen participants who volunteered were Saudi Arabian, aged between 18 and 57 and with a stuttering condition. All of the participants' names have been changed to pseudonyms which they agreed to use for the research.

Table 4.3: Study Participants

Pseudonym	Gender	Age (Years)	Methods of conducting the life	
			story	
Alia	Female	18	Written	
Haifa	Female	19	Skype interview	
Yasser	Male	19	Written	
Fahad	Male	20	Written	
Omer	Male	21	Voice messages	
Sarah	Female	21	Written	
Fajer	Female	21	Voice messages	
Baraa	Male	23	Written	
Tara	Female	23	Voice messages	
Maha	Female	25	Voice messages	
Ali	Male	32	Voice messages	
Abu Abdullah	Male	34	Written	
Al-Anood	Female	34	Written	
Mohammed	Male	40	Written	
Kholod	Female	48	Written	
Rakan	Male	57	Voice messages	

No further comparable variables were included, as no participant information was deemed relevant beyond their gender, age and methods of conducting their life stories. However, certain issues related to their families, education and occupations were presented throughout the findings and discussion if deemed appropriate. As the table clarifies, the majority of participants were aged between 18 and 34, which was possibly a result of adopting Twitter and Snapchat to source the sample; such platforms may not be used by a sufficiently broad age range of individuals to reach them for the research. The restricted number of older participants is a potential shortcoming in this research, although because this study sought different voices of PWS, age was not necessarily a pertinent variable in terms of how adults' stories would differ. Rather, stories within their intrapersonal-external contexts are the aspect that is of interest.

### 4.5: Data Collection: Narrative Life Story

This study employed topical life story interviews as a method for researching the lived experiences of PWS. Research studies have primarily defined the life story and life history as types of qualitative approach that are adopted as a means of investigating people's life stories (Kathard, 2001), in addition to capturing people's meanings, feelings and perceptions concerning their lives (Goodson & Sikes, 2001). McAdams (1993) related how one's life story is a psychological procedure linked with self-narration, which

arises for people during their adolescence or older, while they aim to understand their life's purpose and the meaning.

Consequently, the term 'narrative' or storytelling transcends simply being a research method. Rather, the narrative pertains to human behaviour, because all individuals engage in intrapersonal narration throughout their lives (O'Dwyer et al., 2018). Narration is described as a 'process of responding to the world and building a connection with it' (Tamboukou, 2010, p.171). Developing this perspective, Livholts and Tamboukou (2015, p.43) suggested that:

'Research into people's stories traces the constitution of the narratable self. This self is exposed since birth within the world's interactive scene, as well as via this constitutive exhibition, with oneself coming to desire that the tale of one's own life story is told or written' (p.43).

Accordingly, one's life story is a narrative that individuals opt to convey concerning the life they have lived; it is intended to be as comprehensive and honest as possible, although people typically relate what they recall with regards to their life narrative, while typically conveying what they would like others to know about their stories (Atkinson, 1998). Ultimately, individuals' life storytelling has a greater prospect of representing their contemporary conceptualisation of their life narratives, as opposed to being intended to recall everything as it has occurred during their lives (Rosenthal, 1993).

Reflecting the majority of social studies, participants' storytelling may not be 'neutral', rather it is selective and aggregating (Plummer, 2001). Participants' life stories may be largely selective, to the extent that they potentially distinguish relevant and irrelevant events. The practical result was that the interviewees naturally conveyed their life stories from their perspective as PWS, given their consciousness of the research's focus on stuttering experiences. Consequently, the storytelling represents the participants' overall reconstruction of their past and anticipated future life (Fischer, 1982), during which their storytelling potentially adopts a thematical shape which facilitates the construction of what they determine their pertinent stuttering experiences are. For example, a participant might relate a story chronologically from the past, present and into the future. The life story interview process sought to avoid restricting or directing participants' narratives, instead aiming to permit them to select the stories they deemed to be pertinent; contributing valuable data for this study.

This study is concerned with the participants' narrated lives as related to their broader social context, reflecting the previously implemented process of Rosenthal (1993), as well as Goodson and Sikes (2001). Thus, there is an attempt to understand the manner in which the story is being narrated (Rosenthal, 1993; Bar-On, 2006). Yet, it is not only a case of how the story is narrated—which is pertinent—but how the story is connected to what has occurred during the storytellers' lives in addition to how they have responded towards it are both considered significant. Both the story and the lived life, as they are told by the narrator, are prominent dynamics (Adriansen, 2012). Life stories are changeable, as memories and interpretations of events adapt and change in accordance with shifting values and emphasis (Adriansen, 2012). Life stories are contextual and must be investigated and comprehend accordingly (Goodson & Sikes, 2001; Callewaert, 2007). Consequently, the data obtained from life story interviews could be understood when it is connected to internal and external elements in relation to time. In addition to certain contexts possibly contributing to how individuals are constructing their life story, or alongside their feelings about their stories during the time of interview (O'Dwyer et al., 2018; Germeten, 2013; Adriansen, 2012).

The life story interview approach's aim was to obtain data on participants' life perceptions, while also ascertaining how they make sense of the effect of their intrapersonal, interpersonal and external interactions on their stuttering experiences. In this regard, the interviews were concentrating on the language and Symbolic Interactionism they implement during their narratives and storytelling, as the manner in which they understand their perceptions and interpretations of their life and social interactions (Atkinson, 1998).

It can be worth noting here that academic research studies distinguish the life story from life history. Life story studies aim to understand individuals' positions and perspectives regarding their personal narrated life. Meanwhile, life history research is concerned with understanding the patterns and structures that people adopt as a means of relating their life stories, in addition to how these stories are connected to their broader historical contexts (Adriansen, 2012). The life story interview is more appropriate for this study, given that its aim is not to explore the participants' entire life history, rather it aims to investigate their life stories as they are selected by the participants. Regardless, analysing life stories, whether through life story or life history studies, should involve two levels of

analysis. These are life history analysis and life story analysis (Rosenthal, 1993). The former is adopted for analysing the experienced life as lived, while life story analysis is employed for analysing the narrated life story as conveyed by the storyteller (Rosenthal, 1993). Consequently, the explanation that this section provides is necessary to prevent any confusion regarding the adoption of the terms life story and life history interviews, as well as life story and life history analysis.

### 4.5.1: Life Story Interview Design

One-to-one life story interviews were deemed appropriate for fulfilling the research's aim, namely to understand individuals' perceptions of their lived experience of stuttering. This method enables an environment to be established that promotes an individual's sharing of experiences (Sturges & Hanrahan, 2004). Furthermore, as stuttering typically conveys an emotional response in the PWS (Bricker-Katz et al., 2009), one-to-one interviews are particularly pertinent for this type of qualitative research.

Also, it was left to the participants to determine how and when they contributed to the research through narrating their life story. They were provided with the options of being interviewed via Skype, or sending their life stories in written or voice-recorded format. These various interview types are discussed in section 4.5.1.3. The life story interviews were conducted flexibly with regards to time, with very little time constraints being imposed on the participants for when they should complete their life story. Nevertheless, for the Skype interview the process took around 90 minutes. Contrastingly, those interviewees who sent their completed life story, whether in writing or verbalised, provided feedback explaining that they had spent from one to two hours on the process. The participants' interview experiences was a subject that I raised with them once their topical life story interview had been concluded. The following sections discuss the interview topic adopted when the participants were asked to provide their life stories, followed by the visual material they selected to facilitate their participation, then the participants' chosen interview types while providing their life stories.

## 4.5.1.1: Interview Topic

To obtain a significant amount of participant-led data via this method, the data were collected via a 'topical' life story method (Adriansen, 2012). This involved asking

participants a single open question concerning their life story with stuttering. The topical life story interviews were initiated with the following question:

Keenly think about your own life, including the past, present, and future, as well as about your relationships and your academic, professional, and social life. Then, choose one or more of the provided charts, and write down or draw the significant events or incidents of your life along with referring to the people who played a major role in these events or on you. Feel free to draw any images or even a timeline if you prefer it.

The above question was sent to the participants via Snap Chat messages, alongside the participant information sheet. The participants were provided with the option of selecting their own structure and events of their life stories. Therefore, participants were not asked specific questions, for example 'when did you start stuttering?', 'how did you feel?' and so forth. Consequently, despite the principal research topic being the participants' stuttering experiences, they were not asked to rate their level of stuttering, rather it was left up to them to decide what they wanted to discuss with regards to their life story with stuttering. Ultimately, it was left to the participants whether they mentioned their stuttering's severity or otherwise. This method, which closely reflects that of Rosenthal (1993) and Adriansen (2012) approach, was adopted given that the research focus was on how the participants reconstructed their life story. This might have been related or unrelated to their stuttering's severity. Thus, despite the storyteller and researcher combined being 'collaborators, composing, constructing a story the teller can be pleased with' (Atkinson, 1998, p.9), during this research the life story interviews were overwhelmingly participant-led.

#### 4.5.1.2: Visual Materials

In addition to the interview topic, the participants were provided with the option of three charts (Images A, B and C in Figure 4.4), through which participants could draw and visualise their timeline or lifeline in order to facilitate the presentation of their life story. The participants were permitted to adopt more than one of these charts if they desired. The interviewees were able to amend these charts or draw their own image on a white sheet of paper, as a means of explicating their life story more effectively, therefore strengthening their engagement in terms of shaping their interviews and narratives

(Adriansen, 2012; Sheridan, Chamberlain, & Dupuis, 2011). This made room for various lives, varied stories and their context along the timeline. Bagnoli (2009) and Sheridan et al. (2011) exemplify those researchers who have advocated for time lines' adoption as a means of creating a participatory space, however they provided no clarification in terms of how and why this is the case, or such a timeline's effect on the interview process.

Each chart was devised to represent a manner of perceiving life events and incidents. One of these (Image A Figure 4.4 [A]) presents a line from the birthdate to the present time; this chart exemplifies a typical life story research timeline chart (Adriansen, 2012). Nevertheless, the timeline was further shaped in order to present the highs and lows during participants' lives, without specifying the time intervals; the line was complemented with additional lines, enabling the participants to select alternative paths. Concerning the life story, it was necessary for the timeline's shape to be incorporated as an aspect of this approach, thus enabling investigation of certain participants' life experiences for whom this shape was preferable. Such participants may potentially be deemed as having considered their lives through the 'time', ages or life stages. Numerous researchers have emphasised the value of adopting timelines (see Thomson & Holland, 2005; Wilson et al., 2007; Adriansen, 2012) as a method for encouraging contributors to convey narratives about their lives and previous experiences.

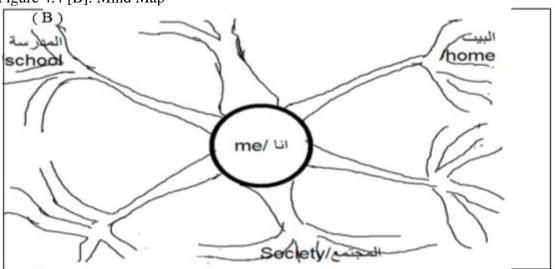
الك الان day of birth

Figure 4.4 [A]: Timeline Chart

The second chart (Image B, Figure 4.4 [B]) presents a mind map, with the participant situated in the centre and connected to all of the events during their lives; albeit with these

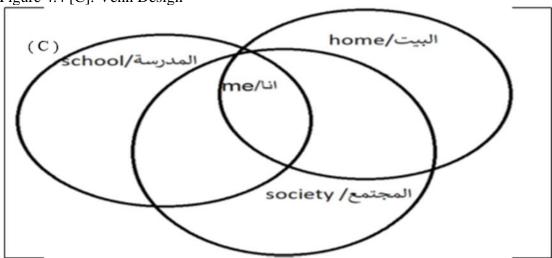
events not necessarily being interconnected. Mind maps are potentially considered as presenting fewer links to time or age. Incorporating this mind map shape is meaningful, because the literature has indicated that interviewees initially completing mind maps tend to identify a higher quantity of unique concepts, while also conveying more in-depth answers pertaining to their experiences during subsequent interviews. Certain participants in the extant literature have clarified that through the preliminary completion of a mind map, they were able to more effectively remember, organise and structure their reflections on previous experiences (Wheeldon, 2011).

Figure 4.4 [B]: Mind Map



The third chart (Image C, Figure 4.4 [C]) comprises of overlapping circles (Venn Design), with the participant situated at the heart of the circles. Such a chart also contains useful data and illustrates relationships, similar to the timeline and mind map, it varies in terms of being reliant upon the overlapping circles to denote numerous kinds of non-hierarchical connections (Wheeldon & Faubert, 2009). This shape may be adopted when the participant is not concentrating on the events and stories' chronological order, cause, or effect, yet may nevertheless have considered the more overlapping experiences throughout their entire life story.

Figure 4.4 [C]: Venn Design



Additionally, the participants were given the option of drawing their life story on a blank sheet of paper, as a means of providing them with requisite space to provide illustrations that more closely convey their thinking linked to their life stories. Such flexibility may fit effectively with other visual methods that research has principally drawn on, for example photographs, which are typically made or created specifically for the research (Sheridan, Chamberlain, & Dupuis, 2011). Five participants adopted the timeline chart, six participants used the mind map chart, four participants chose the Venn diagram, while just one participant opted to draw their life story on a blank sheet of paper.

The aim of giving participants the option of different charts and images to depict their life stories, was to provide a format they felt most comfortable with to describe their social interaction and lived experiences. Furthermore, it was anticipated that participants' extension and elaboration of memories and stories pertaining to experiences would be encouraged (Sheridan et al., 2011), while also aiming to obtain an initial understanding of how participants placed value on their life events, with the participants being asked to clarify why they opted to draw their life stories in the specific manner they did. Ultimately, if research participants engage in the visualisation of their memories, they have the ability to support their thinking as a means of accentuating pertinent aspects and stories relating to their experience (Sheridan et al., 2011; Crilly et al., 2006). Amalgamating visual materials with discussion enables certain layers of past and present experience to be revealed, which may be difficult to represent through language

(Gauntlett, 2007). This possibly encourages participants to take a more active role, given that they can 'recognise their own agency' (Kesby, 2000, p.425); essentially, the researchers and participants are able to increase their reciprocal engagement in the research (Sheridan et al., 2011). Overall, graphic elicitation methods can provide considerable potential with regards to contributing to qualitative research practice in myriad ways, therefore facilitating participants' storytelling and restricting the researcher's adoption of strict control over the interview's various elements (Adriansen, 2012; Wheeldon & Faubert, 2009; Wheeldon, 2011).

The life stories' key points were to some extent established through the charts that the participants shared. The majority of collected life stories were received in a comprehensive and finished form, either verbalised or written by the participants, with me making no or scant interventions. Consequently, the transcripts appeared different and were diverse in terms of their structure, events, feelings and so forth.

### 4.5.1.3: Life Story Interview Types

The life story interviews were conducted online via Snap Chat and Skype. The interview's nature, namely whether they would be oral, written or Skype-based, was determined by the interviewees themselves. The interview types were adapted in accordance with individual preferences with respect to their speech impediment. Table 4.5, presents the type of interview that participants opted for to provide their life stories.

Table 4.5: Participants' Choices of Interview Types

Written Life Story		Oral Life Stor	Oral Life Story		Skype Life Story	
Pseudonym	Age (Years)	Pseudonym	Age (Years)	Pseudonym	Age (Years)	
Alia	18	Omer	21	Haifa	19	
Yasser	19	Fajer	21			
Fahad	20	Tara	23			
Sarah	21	Maha	25			
Baraa	23	Ali	32			
Abu Abdullah	34	Rakan	57			
Al-Anood	34			_		
Mohammed	40					
Kholod	48					

Written Life Story: Nine participants (five males and four females) opted to write their life stories via Snap Chat instant messaging. Accordingly, this may be considered as a

written data collection method. Written interviews maintain the data's audit trail one step closer to the interviewees (Hamilton & Bowers, 2006), because no interview transcription is required. Potentially, this is a beneficial aspect of written interviews, due to scepticism regarding transcription practices that suggests it may involve data's 'tidying up', as well as eradication of its 'raw form' (Seale, 1999). Moreover, transcription reliability is a potential problem (Kvale, 1996) which can be eliminated through written interviews. Furthermore, when participants write rather than verbalise their life stories, this possibly provides them with a more adequate amount of time to consider their life story's structure during the process, verifying whether they consider it to accurately represent their life stories. In this regard, a strong type of raw data (written autobiography) is provided, conveying how the participant wishes their life story to be read or known at the time of writing.

With the fundamental data for this study focusing on participants' adopted language and symbols that allow comprehension of their life experience with stuttering, it appeared that written life stories could capture that essence most effectively (Hamilton & Bowers, 2006). Written communication is deemed to be more abstract and objective (Kvale, 1996), meaning that my understanding of the written life stories has a greater likelihood of being informed by the words I read and my comprehension of them, alongside the feelings and thoughts.

Oral Life Story: Six participants (three males and three females) opted to audio-record their life stories. Each participant provided a voice recording via the Snap Chat voice message feature, sending their stories as several voice messages. This approach potentially facilitated the participants' production of their life stories at their own pace and their retheming of the narrative. Additionally, oral communication is generally considered as less abstract and offering a closer reflection of the individual's real world (Hamilton & Bowers, 2006). Indeed, participants' feelings, perspectives and so forth may be communicated through their voice rhythm. Subsequently, this may enhance my understanding of the life stories' associated meanings. My understanding of the oral life stories pertains to my responses to the participants' voices, alongside my own appraisal, feelings and thoughts.

Most research participants typically sent separate voice messages concerning specific life subjects, stories or aspects of them, which covered their life stories with stuttering. In accordance with this process, I typed out the transcripts for these vocalised life stories. Fortunately, the audio recordings were very clear, because participants used their smartphones to record themselves. The clarity may have also been linked to the participants' consciousness that their voices were being recorded in order to be heard; meaning they were unusually conscious of their voice rhythm and sentences. This potentially diminished the risk of mis-transcription by the researchers (Crichton & Childs, 2005). Additionally, even during the production of their voice-recorded oral life stories, participants had the opportunity to organise their speech, being able to possibly delete or re-record some of their voice messages prior to sending to the final version to me. Subsequently, this confirms that online voice recording software, for example Snap Chat audio-recording tools, present a flexible and straightforward method for permitting PWS to tell their life stories in their desired manner.

Skype Life Story: Only one participant opted for a Skype voice call interview, although this did not include a video. Thus, this Skype life story was more akin to a phone interview. Ultimately it offered the advantages of a phone interview with regards to permitting voice interaction between the participant and the researcher (Hanna, 2012). Nevertheless, during the Skype interview there is potentially reduced time for the participant to appraise their own personal storytelling structure, therefore the participant may have related her life story with little consideration of their decision to include or exclude stories or events from her life story. This potentially resulted in the interview taking more of a natural conversation format. This interview may be deemed comparable to the voice-recorded life stories, because of the participant's ability to talk continually about her life story with limited intervention. Transcription of the interview was necessary following the Skype call's completion.

#### 4.5.1.4: The Effectiveness of the Data Collection Methods

The study's focus was how the interviewees rationalised their stories, as opposed to simply the actual narratives themselves. The participant presented how they perceived their life stories. Additionally, despite this conversational style potentially affecting or encouraging the participant as they related their stories to me, no marked difference was apparent between the Skype interview and the oral or written interviews in terms of their length or depth. Given that the participants sent their complete life stories, it was

unnecessary for me to interrupt their storytelling. This enhanced their chosen data collection method and design's value and significance, providing the participants with sufficient flexibility in the sense that they could write, verbalise and draw their life story in a location and at a time of their preference. They faced no interruption or interaction that might have influenced their personal self-narration of their life story.

Trade-offs are evident with regards to online interviews' advantages and disadvantages, although the strengths outweigh the weaknesses (Hanna, 2012). Snapchat interviews are analogous to Skype interviews, although having the further advantage of providing a more flexible and comfortable environment for certain participants. Additionally, they are advantageous for eliminating the ethical requirements linked to the handling of sensitive personal data, for example postal addresses, as well as for facilitating communication with participants located at a distance (Hanna, 2012). Furthermore, Saudi Arabian social customs do not permit unsupervised interactions, in closed spaces, between men and women who are not relatives. To account for this, and with the participants' consent, a technological solution for conducting remote interviews was adopted. Moreover, the obtained data was ultimately fairer in terms of collecting and representing both men and women's perspectives, because both were able to be interviewed via Snapchat and Skype.

Furthermore, Snapchat and Skype interviews offered the benefit of communication across significant geographical distances, thus eliminating potential travel costs. Nevertheless, such interviews do not necessarily permit observation of subtle interactional cues (Mann & Stewart, 2000). Throughout an interview, body language is a particularly significant cue for gauging and/or monitoring a participant's emotional status. I needed to be mindful of this aspect, on the basis that PWS regularly employ conscious or subconscious gestures, for example face or hand movements, to aid their expression of a word or thought that is proving challenging for them to articulate in speech. With the aim of mitigating the limitations of remote interviewing, I regularly asked the participants if they were comfortable and relaxed during the interviews (see the ethical consideration, Section 4.9). Additionally, all life stories were completed at the time and pace that best suited the participants, with 15 out of the 16 life stories sent to me as voice recordings or written messages without direct interaction between the participants and myself. This potentially

assisted with diminishing any stress and anxiety for the participant stemming from the interview process.

The research and interview topics were initially composed in Arabic. Thereafter, they were translated into English to enable their reportage in this thesis and elsewhere, although the Arabic versions provided the participant-facing material. Consequently, I was conscious that English to Arabic translations and quoted material (translated from Arabic to English) might not be rendered perfectly. Irrespective of this, I sought to preserve the underlying meaning, adopting transparent methods; this was measured through applying of the 'forward and back' translation strategy (Degroot, Dannenburg, & Vanhell, 1994), which involved asking a colleague with native Arabic knowledge to compare my rendering of the Arabic to English transcript with the original, thus verifying the translation's accuracy. Translation problems commonly arise from language's idiomatic usage and cultural concepts, which sometimes fail to be adequately rendered from one language and culture to another (Wang, Lee, & Fetzer, 2006). Therefore, a limited interpretation may be required so that the original text's meaning can be conveyed, which necessitates the adoption of a semi-idiomatic approach to the translations.

# 4.6: Methods of Data Analysis

In order for PWS' experiences to be understood, both visual and narrated (including written) life stories were analysed. Rosenthal (1993) and Rosenthal and Fischer-Rosenthal's (2004) life story analysis procedures were adopted to drive the analytical process. Meanwhile, the visual resources were analysed through applying Adriansen's (2012) and Saldaña's (2013) strategies. An overview of the data analysis strategy is presented in Table 4.6.

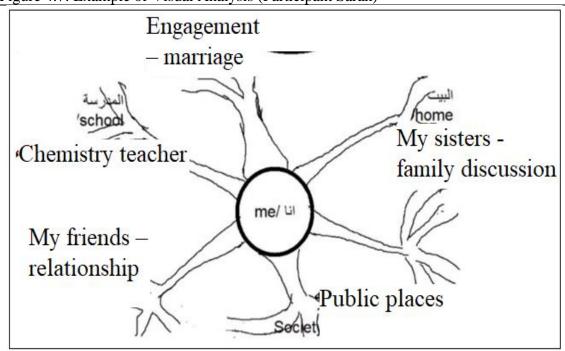
Table 4.6: Data Analysis Strategy

Data Type	Study	Analytical Strategy
Visual materials	Adriansen (2012) Saldaña (2013)	Visual materials were analysed by describing them, then connecting them to the narrated life stories (holistic perspective)
Narrated life stories	Rosenthal and Fischer- Rosenthal (2004) Rosenthal (1993)	Life story and life history analysis, including Thematic Analysis and Symbolic Interactionism

### 4.6.1: Analysis of Visual Materials

The visual material's analysis was undertaken by describing them. This description was underpinned by what was seen in the visual material alongside participants' clarifications of the visual information they presented. Given that a sole reliance on visual information as the primary material for life story studies may not be meaningful (Adriansen, 2012), the visual resources need to be analysed on the basis of a holistic strategy (Saldaña, 2013). When visual resources, for example personal timelines, are seen alongside the associated interview narratives, this is the sole means through which a holistic understanding may be reached (Berends, 2011). Therefore, every respondent's visual data was connected to their overall life story during the assessment. Throughout the process of situating the participant's chosen narrated events in relation to themselves, as well as the participant's situation within their overall life stories, the language they adopted was crucial to appraise. This enabled the life story analysis of the respondents' narratives to reach a more comprehensive level of understanding. Subsequently, the visual material analysis was verified by the respondents themselves. (Figure 4.7) provides an example of the visual material analysis.

Figure 4.7: Example of Visual Analysis (Participant Sarah)



Sarah described this mind map as reflecting the roots of a tree, with each root connected to a different feeling. Based on the above chart and Sarah's explanation, it is evident that Sarah perceived herself as a tree that has been shaped and affected by her life events, in addition to the feelings stemming from what had happened to her. On the chart's roots, Sarah wrote the significant events that had influenced her life story. At home she felt more negatively affected by her sisters and their comments, while her school life was characterised by negative experiences due to her Chemistry teacher's attitude. Additionally, her friends and relationships informed her life experience. Being in public settings has provided a space which influenced Sarah's cognition regarding her stuttering experience, while her future concerns relate to getting engaged and married, as she remains single.

Note: Sarah opted to concentrate on those events that potentially had a **negative effect** on her stuttering experience. For example, despite Sarah's mother being supportive, as explained to me in the narrative data that Sarah provided, she chose not to highlight this on the chart.

Figure 4.7 presents an example of the visual resource results written presentation, with the entire life story being linked to the visual resources' characteristics and evaluation. Initially, the English translation of each of the written Arabic words was carried out. Following this, the charts were appraised and analysed, drawing on the respondents' explanation themselves, so as to formulate a holistic understanding. The chart's specific depicted components were interlinked and clarified, with the overall life story then evaluated in relation to these components. Accordingly, appraising the visual resources via the respondent's drawing was an aspect of the analyst's role, whether the manner in

which the elements have been depicted or what precisely has been drawn or written down (Adriansen, 2012). Following this, a written presentation of the results was composed, with the prominent themes (in bold) emerging from the respondent's specific sentences and words used. This permitted trends in the respondents' life stories to be identified and condensed. The approach to connecting the life story analysis to the visual materials was influenced by the latter's adoption by respondents, alongside the variations in their adoption.

#### 4.6.2: Analysis of Narrated Life Stories

The life story method was employed for both the data collection and analysis processes, including obtaining information as life stories from the participants, while situating these stories within the broader period, context and self-narrative of the participants via the life story analytical process (Plummer, 1995). Narrative analysis, among other typically implemented qualitative analysis methods, have certain commonalities with life story analysis, with all of them pursuing a shared aim (Earthy & Cronin, 2008). Regarding narrative analysis and life story analysis, each aims to understand why and how individuals use a story or several stories to discuss their experiences, during the process of analysing interview data. Furthermore, understanding the meaning conveyed by individuals was pursued via Thematic Analysis in both approaches, making it a principal shared methodological aspect.

Nevertheless, the 'life history' assessment stage undertaken as part of life story analysis is the foremost divergence away from narrative analysis, given that it involves the participants' life storis events, in addition to the chronological and logical arrangement being reconstructed as an aspect of the analytical process (Rosenthal, 1993, 2006). As Hunter (2010) described, life story analysis includes: inter-narrative comparison' specific text analysis; life history analysis; Thematic Analysis; alongside an appraisal of biographical information, which are all incorporated into Rosenthal and Fischer-Rosenthal's (2004) and Rosenthal's (1993) analytical strategy. The subsequent sections present the life history analysis, followed by the life story analysis, which includes information on the Symbolic Interactionism and Thematic Analysis procedure.

### 4.6.2.1: Life History Analysis

Life history analysis involved a restatement of the life stories' chronological order, in addition to evaluation of the previous meanings, values and feelings of what had happened (Rosenthal, 1993). With real events being reformulated by people into narratives based on their personal experiences and understanding, personal narratives and real events may be distinguished according to Rosenthal and Fisher-Rosenthal (2004). The participants in this study structured the initiation and conclusion of their stuttering stories in numerous ways. Typically, certain interviewees did not initiate their life story at birth, instead they initiated it from a particular point or story in their lives or memories. Therefore, it was appropriate for me to undertake the process of chronologically analysing the participants' stories as a preliminary analytical stage (Adriansen, 2012).

The first aspect to be mindful of while conducting a life history analysis is not searching for the truth or accuracy of the narrative with regards to what genuinely occurred at the particular point in time during the participants' past life (Rosenthal, 1993). Rather, the principal concern is to understand 'why' the interviewees constructed their current narratives in the manner that they did, which potentially enabled understanding to be strengthened of what the participant's current perspective is, having appraised their selective stories. As a researcher at this stage, I considered each life story in its entirety and evaluated the constructed stories in relation to their time (the chronological order) and location (home, school, workplace, and social settings). Moreover, I compared my evaluation and interpretation with the participants' reconstruction of their life stories. The entire life history analysis was sent to the respective participants in a form similar to that in Appendix D (page 287), with each participant needing to respond and confirm that the life history analysis accurately reflected their life story. Only after their confirmation were the remaining analysis stages initiated. A section of respondent Mohammed's life history analysis is presented in Table 4.8. The analysis of the respondent's words is presented in column A, while the analysis of the respondent's story as a chronological series is conveyed in column B.

Table 4.8: Example for Interpretation of the Chronological Order

#### [A] The structure of Mohammed's life [B] The structure of Mohammed's life story as related by himself history, in chronological order from past to present Life story begins at the age of seven. Age seven is when Mohammed began Aged seven, Mohammed knew about his understanding that he had a stutter, despite his stuttering potentially having begun speech problem because of his peers mocking him. before seven years of age. Of course, Due to his negative social interactions at Mohammed had life experiences prior to school and during family gatherings, seven years of age, yet he opted to begin his life story then because that is when his Mohammed started engaging in avoidance behaviours during his childhood. story with stuttering began. Subsequently, this possibly indicates that Mohammed situates his stutter as a central aspect of his life.

During this stage, I analysed the data's form and structure, evaluated the expected meanings (or feelings stated) linked to their previous experiences at the time they occurred, while also exploring the meanings behind participants' construction of their stories (Rosenthal, 1993). This approach was in accordance with that of researchers such as Bar-On (2006) and Rosenthal (1993). This facilitated an analysis of how participants constructed their life story, in addition to the value they placed on the interactions, events and stories comprising their lived experience.

For example, stories of a childhood experience of being bullied at school is undoubtedly a negative experience, thus I concluded that the participant was unhappy during that period (life history analysis). The participant potentially discussed being bullied as something they deemed to be a challenge during their process of pursuing a better future, or as a turning point, or related how they continue to experience the same feelings when recollecting their negative childhood stories. Consequently, comparing my interpretation with participants' present feelings enabled clarification of the contemporary meanings underpinning participants' construction of their life stories. The rationale behind adopting this approach was to contrast my reconstructed chronological order, to the greatest extent possible, with the actual order of events as arising during participants' lives (Rosenthal, 1993; Adriansen, 2012).

### **4.6.2.2:** Life Story Analysis (Thematic Analysis)

Having conducted the life history analysis, including the reconstruction of their life stories' form and structure as they were potentially lived, all of the narrated life stories were analysed thematically (Thematic Analysis) (Braun & Clarke, 2006), in accordance with Rosenthal's (1993) life story analysis. This concerned the manner in which the stories were constructed and thematically arranged by the participants in relation to their 'current' narrated life story. Thematic Analysis may be implemented for formulating a conclusion in accordance with the data's 'deep' meanings (McIntosh & Morse, 2015), being a subjective process that may take various forms (Braun & Clarke, 2006). In this study, the meanings generated from the Thematic Analysis were connected to an in-depth cognisance of the contexts of the Social Relational Model of Disability (SRMD) and Symbolic Interactionism in relation to the PWS' life stories (Saunders, Lewis, & Thornhill, 2009).

Indeed, the Thematic Analysis requires the identification of significant and pertinent themes as they emerge, a process which is evidently challenging to undertake in advance. Therefore, an inductive approach was implemented, which is reliant upon patterned processes' delineation (Ernest, 1994). Coded information was extracted that pertained to participants' perspectives and subject knowledge of their stuttering experiences. This covered the documentation of themes identified during the life story interviews, the cross-correlation of their interrelation significance, alongside the adoption of pertinent category frameworks. The following sections clarify the relationship between Symbolic Interactionism and Thematic Analysis as analytical procedures.

**Symbolic Interactionism** (Plummer, 1990), as an analytical approach, has been implemented throughout the analysis procedure. It was used as a means of interpreting the meanings underpinning the participants' life stories, as well as to comprehend how people understand themselves and their environment, via symbols and language (Blumer, 1990). The participant's adopted language potentially reflects specific meanings and emotions that they aim to convey to various listeners (Giele & Elder 1998: 26), as well as their interpretation of their external interactions (Lit & Shek, 2002; Daniels et al., 2006). Thus, PWS themselves are considered to be a crucial aspect of their assessment and perception of their experiences as either generally positive or negative, because it is them

who are construing or creating meaning from them. Consequently, although people may experience similar events, their individual interpretations of such events might differ. Accordingly, the event becomes a component of their unique lived experience (Plexico, Manning, & Dilollo, 2005).

Therefore, the meaning of the words that a participant assigns to their experience requires holistic understanding via their connection to the participant's overall life story (Corcoran & Stewart, 1998; Bricker-Katz, Lincoln, & Cumming, 2013). With this aim in mind, analysis and discussion of the participants' life stories has been undertaken through appraising their life story events as components connecting their entire life story; only via such a process is it possible to formulate a perspective and understand each life story's entire picture (Klompas & Ross, 2004). This holistic, contextual analysis of every life story included their significant characteristics, for example key themes, identifying transitions between the themes, episodes apparently contradicting themes with regards to their context, mood or evaluation by the narrator, alongside paying attention to previously unmentioned issues.

Thematic Analysis Procedure: In accordance with Rosenthal (1993) and Rosenthal and Fisher-Rosenthal's (2004) approach, I developed an initial insight into the participants' experiences via the process of understanding the meanings of their words and stories at the time of their narration, in addition to their stories' thematical and temporal order at the point at which their life story was narrated or written (Rosenthal, 1993). Both visual and narrated data was utilised for clarifying the construction of participants' life stories in relation to the SRMD theory, as alongside the application of the Symbolic Interactionism approach (Plummer, 1990). Table 4.9 provides a summary of the Thematic Analysis process.

Table 4.9: Summary of the Thematic Analysis Process (Braun & Clarke, 2006)

Thematic	Description	
Analysis process		
Organise the data	Worked with the field notes from the life story analysis;	
	Organised the data, including the importing and copying of the	
	written life stories into MAXQDA Software. Transcribed the	
E::	oral life stories.	
Familiarisation	Worked with one life story at a time, familiarised myself with	
with the data	the data through reading it through several times as necessary;	
	Wrote down each idea or thought that developed while reading	
	the data.	
Coding	Labelled each part of the life story, coded the words and	
	language used depending on their meanings;	
	Produced memo notes about the participants' reconstruction of	
	their life stories;	
	Re-read the life story to ensure that each aspect of the narrative	
	is labelled and coded.	
Generating initial	Re-read the labels and codes, categorising them in groups in	
themes	accordance with the research questions.	
<b>Reviewing themes</b>	Engaged in informal discussion with each participant regarding	
	the interpreted themes and visual description.	
Defining and	Evaluated the meanings from the generated categories across all	
naming themes	of the life stories. This process was followed in order to name	
	the wider themes, which may be related or unrelated to typical	
	themes presented in other research in the stuttering experience	
	field.	
Writing up	Wrote up the findings as related to the research questions.	

#### 1- Data Transcription:

The Oral and Skype life story interviews were transcribed in their entirety (Rosenthal, 1993), with the transcripts being typed into Microsoft Word. The transcription process enabled me to acquire a richer clarification of the data for the oral interviews, while the written life stories were copied from Snap Chat into Microsoft Word (see Appendix E, page 289, for the interview transcripts). Afterwards, I assigned each transcript a pseudonym of their choosing which was included. This enabled interviewees' narratives to be accurately reflected, as well as any relevant conversational exchanges. Additionally, it enabled me to organise the data and establish a sound grasp of how the participants' life events were interconnected and linked to their social lives. From the participants' perspectives, all notes and initial ideas pertaining to the analysis were incorporated. Therefore, during the preliminary analysis stage, I made reflexive notes regarding the

interaction of salient ideas, prominent themes and analytical approaches, with forward and backward translation also being carried out.

The coding software MAXQDA was implemented as a means of facilitating the transcripts' data coding, given its adaptability to Arabic language. MAXQDA is designed for analysing qualitative data (Schönfelder, 2011). Indeed, it is analogous with NVivo in terms of its set of features, for example labelling, coding and memos. Nevertheless, MAXQDA may be adopted instead of 'documents', given that the software does not just permit document handling but also multimedia files to a certain extent (Schönfelder, 2011). In MAXQDA, the two left-side windows are devoted to listing the coding system in the lower window, while the project file's included sources are presented in the upper-left window. Furthermore, MAXQDA permits text files and pictures to be imported. The MAXQDA menu buttons are labelled primarily with the established terms.

#### 2- Familiarisation with the Data

Throughout and following the transcription and analysis process, I carried out the second stage which comprised of reading and continued familiarisation with the data. This stage involved reading and re-reading the transcripts as many times as necessary, until I was certain that I had thoroughly grasped them. I also searched for general ideas and made notes for my own personal use that highlighted where issues were potentially connected to the research question.

#### 3- Coding

This stage included the transcripts' line-by-line coding for each sentence or concept, as well as the analysis of participant's reconstruction of their life story. In accordance with Saldaña (2013), In Vivo Coding was implemented, with respondents' own words being drawn on to develop the codes rather than the words of the analyst, due to this study emphasising the respondents' voices. This analysis phase involved highlighting particular 'emotions', 'experiences' and other significant words, concentrating on coding a single case study, while also summing up every line, sentence or event using the respondents' own terminology for the codes. These procedures were found to be particularly advantageous. Additionally, broader concepts and themes were devised from those codes and labels that conveyed the essence of an event or aspect's significance. During this

analysis' preliminary phase, salient quotes and those which summed up every life story were identified. Table 4.10 presents an example of this process.

Table 4.10: Data Coding Example for Respondent Mohammed

Codes	Text extracted from a transcript
Fears	After having graduated from high school, I still am very afraid of
	talking in front of others. It makes my heart beat very fast, and
	expressions of confusion cover my face. My stuttering problem
Work -	very much impacted my job searching as well, since it has let me
Job interview	down in various interviews, in which I become <b>nervous</b> and am
	unable to express what I wish to say. I am very thankful that I now
<b>Avoidance</b>	have a successful job, although I still try as much as possible to
Hide the Stutter	avoid meetings and talking in public because
NI ( FICC )	I don't want them to know that I am a stutterer. Sometimes I
Negative Effect	have something to contribute to meetings but I choose not to, which
on Job	I think has affected promotion for myself.

Table 4.10 presents an aspect of Mohammed's life story, relating to his employment and career. 'Work' was the most prominent label assigned here. 'Social interaction', 'fear' and 'job interview' were the codes linked to this label. Mohammed confronted challenges during his work interviews and social communication, with his emotions and reactions to these being conveyed through highlighting in bold the particular terms and sentences used by Mohammed. Furthermore, 'avoidance' is a well-established theme in the literature pertinent to stuttering (for example, Connery et al., 2019; Daniels, Hagstrom, & Gabel, 2006), which was identified in the text through Mohammed's adoption of the term 'avoid'; this was underlined and highlighted in bold. All aspects pertaining to how Mohammed's stuttering experience was affected by intrapersonal-external engagement were coloured in green. One example is how Mohammed explained how he sought to obscure his stutter, through evading social engagements.

During this stage, I analysed how people construct their life stories (Plummer, 2005). Given the qualitative nature of this research with a focus on PWS' experiences, this is indescribable without assessing how participants used language and symbols to construct their stuttering experience. Therefore, it was necessary to meticulously read through each participant's story to clarify what value they placed on each aspect of their story, in addition to how it related to their overall life story. It was crucial to heed the language adopted by a participant during their story's description; this language is fundamental for

clarifying how they felt about an event at the time that it occurred, or how they felt about it presently. For example, the participant may have said, 'how I felt' or 'how I think I felt'. My focus was on the participants' stories to understand how they talked about themselves, alongside their social, cultural and environmental contexts. Table 4.11 presents an example of using memo coding data for writing comments pertaining to a participant's reconstruction of their life story, namely their feelings regarding previous events.

Table 4.11: An Example of Analysis of a Participant's Reconstruction of their Life Story

Memo coding	Text extracted from a transcript
Mohammed's	Mohammed: I experienced so much pain, oppression and injustice that
current	it severely affected me at school. I would just cry, like I am now. <b>These</b>
feelings	childhood memories still make me sad to this day and I cannot
about his	forget them.
childhood are	The researcher: Why not?
the same	Mohammed: Perhaps because, when these things happened, I did not
	try to defend myself. I often wonder, if I had fought back, maybe my
	childhood memories would not be so bad. Throughout elementary
	school, I would not talk to anybody or engage with anyone if it would
	result in conflict because I knew it would cause me to stutter due to the
	stress, in fact these childhood memories are still similar to what I
	experience now.

Table 4.11 provides an example from Mohammed's youth, showing how his every day and school experiences were presented by him as being challenging, although whether his childhood also involved positive or supportive individuals was not something that Mohammed discussed. Accordingly, the way in which his difficult experiences had an enduring effect was the narrative that Mohammed developed based on his reformulation of childhood recollections. His current conceptualisation of his youth remains unaffected by any positive events from that time. In this regard, any positive events' impact is outweighed by the marked effect of his detrimental experiences. As Goodson (2010) proposed, a concern with what is not being narrated as well as what is should be considered as essential during evaluation of the structuring and construction of narratives. Furthermore, Brannen (2013) believed that the structure of stories is significant. On this basis, the overall life stories were engaged with in order to engage in contextualisation of the respondents' experiences and perspectives during the analysis. The different events' interrelationship in the respondent's life story, as related by them, was analysed to investigate the rationalisation of these events.

#### **4- Generating Initial Themes**

The fourth stage involved the generation of the initial themes, entailing an analysis of the codes depending on their meanings as the basis of categorising them into groups, which represent the initial themes. I interpreted the codes' meanings, which were generated during the coding stage, as well as through using one phrase or sentence to categorise similar or related codes into groups. Categories were labelled using particular words or sentence tags in order to differentiate between elements as they pertained to the analysis, enabling the identification of significant data characteristics in the form of the interview themes (Saldaña, 2013). Following this their data was assigned to the most appropriate grouped categories. Each group represented a theme or subtheme comprising of the codes that referred to the meaning of the themes. Figure 4.12 provides a clarification of the process of generating themes through presenting a simplified example.

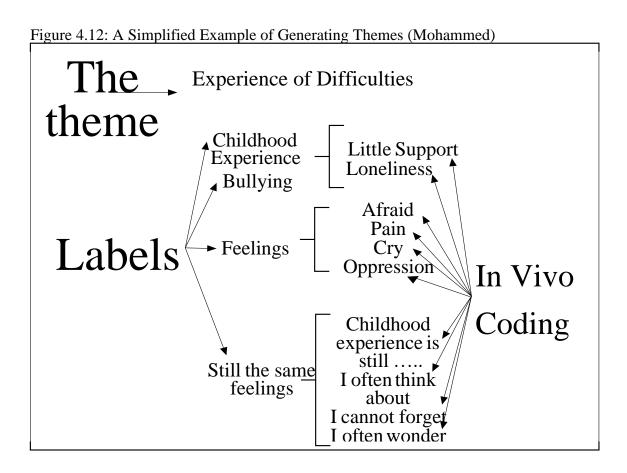


Figure 4.12 clarifies how the coding process involved In Vivo Coding, through which the participant's words 'still the same' and 'pain' were drawn on. Following this, these codes were labelled using a title that identified their referral to the 'impact of his childhood memory'. Subsequently, the theme was named to represent what these codes mean with

regards to Mohammed's life story; because Mohammed discussed his childhood memory as continuing to negative affect him, an appropriate theme name was considered to be 'Experience of Difficulties'.

#### 5- Reviewing the Themes

To verify my understanding of every life story, the analysis was appraised by the respective respondents. This is significant because my personal understanding of the life stories established the foundation of the analysis, alongside my familiarity with Saudi Arabia's cultural and social environment. Ultimately, the data analysis process may be enhanced when the respondents' voices are genuinely conveyed and they are able to contribute to an aspect of the analysis procedure (Ritchie & Barker, 2005). Alongside the appraisal of the themes derived from the analysis, this phase also ensured that the respondents' perspectives and voices concerning their stuttering experiences were being accurately conveyed. This process was undertaken via Snap Chat, with each respondent receiving the set of derived themes, select quotations from their life story, as well as some of my analysis and understanding. The respondents offered their opinion of whether my understanding of their life story was accurate, while they were also provided with the opportunity to provide further feedback or clarification.

#### **6- Defining and Naming the Themes**

Having completed the discussion between the participants and myself as a process of reviewing the themes, all of the themes generated from the analysis of the participants' life stories were appraised. The holistic meanings of the life stories were honed to mould the final findings' generated themes for every participant. I re-read each transcript, coding the outcomes and generating themes as an aspect of the final review stage. Subsequently, themes were generated across all of the life stories, with estimations carried out to apply the data in an optimal-use manner. This enabled a response to the research questions, with a revision of the candidate themes and subthemes as required. Lastly, the final themes were named through using appropriate terms and phrases representing the participants' stuttering experiences. Table 4.13 provides an example of the generated themes and subthemes.

Table 4.13: Example of Generated Themes and Subthemes

Theme: Avoidance

Subtheme:

- Avoidance in social settings
- Avoidance in school
- Avoidance in the workplace

Theme: Experience of Difficulties and Challenges

Subthemes:

- Childhood difficulties
- Life challenges

Thus, avoidance was considered to be a theme due to it being generated through a number of the participants mentioning it during their life stories. This was also the case for the theme of 'experience of difficulties and challenges', although this theme was also a type of narrative that certain participants adopted when they reconstrued their life stories, in order to convey their experiences' challenging nature. Analysing the participants' type of narratives is further discussed below.

### 4.6.3: Analysing the Types of Narrative

In order to respond to the second research question, a second round of analysis was undertaken as a means of interpreting the connotations of participants' words and sentences, as aspects of their life stories' entire context. Symbolic Interactionism was also applied to holistically understand participants' formulation of their perceptions of their stories (autobiography) (Ball & Goodson, 2005). This stage entailed allocating each life story a title or titles based on a single word or sentence which encapsulated the life story's principal underlying idea or ideas. Examples include, 'Childhood memory', or 'The turning point was when she accepted her stuttering', or 'Academic difficulties and resilience'.

Subsequently, a definitive list of the life stories' titles was established, after which the grouping of those life stories with related titles was carried out. Each title group was named as a type of narrative used by the PWS to present their life stories. For example, titles such as 'long-life lasting negative childhood memory' and 'not able to cope with stuttering', were grouped under the 'narrative of difficulties and challenges'. Having grouped the life stories into various narrative types, I appraised the life stories placed

within each group, aiming to connect individuals' perceptions of their stories to 'the types of narrative'. This aimed at identifying a connection between the narrative type and individuals' similarities, in addition to the variations in meanings derived from each life story, which might have contributed to moulding their personal narratives. Therefore, the developed categories and themes were established as significant and faithfully representative of all participants' life stories, as well as having pertinence to the research questions and the manner of the life stories' interconnectedness. Accordingly, I was able to identify the narrative types that participants adopted in order to convey their life stories, which were then presented.

In conclusion, following the life story analysis method, which included life history analysis and Thematic Analysis and engagement with the visual materials, was appropriate for understanding participants' perceptions of their lived experience of stuttering, and understanding how they reconstructed their life stories.

#### **4.7: Pilot of the Interview Process**

One individual was involved in the pilot research, which was a life story interview on the subject of stuttering. In accordance with Thabane et al. (2010), prior to the main interview process involving 16 interviewees, the research methodology and method was tested through the pilot. Evaluation of the interview procedure, the emotions of the interviewee, whether sufficient information relating to stuttering experience life stories would be obtained, in addition to the analytical procedure being practiced, were all objectives of the pilot study. A Snap Chat social group for PWS was engaged with in order to select the interviewee, a 26-year-old man from Saudi Arabia. Because the participant was in Saudi Arabia and I am in the UK, Skype was used to carry out the Arabic language interview.

Ethical concerns, the principal interview questions' standard, as well as the interview procedure, are the three main aspects that must be appraised in relation to the life story interview. Regarding the interview procedure, I made contact with the interviewee as a means of introduction, explaining the research aims and subject to him. He appeared enthusiastic about being involved and friendly. So that the interviewee could consider his answers and as a means of mitigating any anxiety, a week before the pilot study was

carried out, the participant was given the interview question. Prior to explaining his life story during the interview, the participant presented his narratives using the question chart and sheet. Consequently, the interviewee's consideration of his replies and what he wanted to present was facilitated through the pre-interview provision of the interview topic. Therefore, I repeated the process of providing the interview topic and question to the interviewees a week before the interview during the main study, because this reduced the stress they might have felt while respecting their right to know what the interview content and discussion would be about. Moreover, it would be their prerogative whether to prepare for the interview beforehand through consulting the interview topic in the week before the interview.

The main interview question was concentrated on the life story of the interviewee. The previous and present experiences of the interviewee could be sufficiently discussed through the major question. Life stories that were lengthy and detailed were presented by the interviewee. Stuttering-related experiences were principally being discussed by the interviewee, meaning that the subject was an effective focus even though the stuttering life stories were not directly enquired about. Thus, the stuttering aspects of his overall life story were not compelled out of him, because future aims, his career and other notable parts of his life were also discussed by the interviewee. Lastly, in terms of the study subject, the transcript has incorporated all pertinent narratives and experiences. The suitability of the open-ended questions and main question posed is apparent, because queries or myself did not affect the interviewee's position, with their personal views and experiences being discussed.

Concerning ethical issues, there seemed to be no anguish or upset caused by the life story interview procedure for the interviewee, which went as planned. The right to decline a response to any questions, to alter the queries or to stop their involvement at any point was explained to the interviewee. However, the interviewee was proficient in telling his life story, while he also provided positive feedback on the process following the interview's conclusion. Clarity and understanding of the principal interview question, as well as what was required from him, was indicated by the interviewee. No request to end participation in the study has been received, nor have any issues been raised by the interviewee. Each of the main study's interviewees will not be represented entirely by the pilot interviewee, given the variations in personal character. Even so, whether the

interview queries have any major problems may be pointed out during the pilot interview. Consideration needs to be given to personal variations in the interviewees. Additionally, any individual influences of myself, as well as the transcript production process, have been effectively considered in relation to ethical issues.

Financial and time savings were made by undertaking the interviews via Skype. Furthermore, the interviewee could select a more appropriate time for them to participate. It was possible to avoid the costs of travelling to meet an interviewee, when they were able to stay at home and participate online, with just one hour necessary to complete the interview. Additionally, physical interviews can lead to anxiety and stress, which was mitigated through carrying out Skype interviews. The pilot study indicates that the face-to-face interview process was sufficiently replicated through the significant degree of communication that occurred online with the interviewees, despite the removal of the opportunity to develop a rapport with the interviewee one-to-one in the offline environment.

#### 4.8: Trustworthiness

Qualitative research as a form of social phenomenon research (involving individuals) is reliant upon subjective interpretation, therefore such studies' results are not intended to be generalisable, rather they must be considered 'trustworthy' (Howell, 2013). Trustworthiness has been defined as a qualitative research substitute for validity and reliability (Lincoln & Guba, 1985; Morrow, 2005). The indices upon which trustworthiness is measured include adequate data, interpretation, subjectivity and reflexivity. Trustworthiness does not focus on fact-finding, rather it emphasises honesty in production. Ultimately, research data should be pertinent to other studies (namely, it should bridge existing gaps in the literature), while also being credible, transferable and verifiable (Lincoln & Guba, 1985).

As Howell (2013) noted, researchers must remain cognisant of 'reflexivity', which is to say, "how humans are constructed in a social construct and at the same time we are acting as constructing agents" (Howell, 2013, p.185). Moreover, it necessitates 'reflexivity' concerning how research is performed and interpreted. I ensured that the data was legitimately captured, while also acknowledging that data similarity is not a prerequisite

condition for this process. I did not alter, influence, or conceal any of the participants' responses; as outlined earlier, the participants had the ability to write or recode their entire life stories without direct interaction with me. Thus, the data collection's trustworthiness may be established through avoiding leading questions, as well as engaging the participants in selecting their way of constructing and telling their life stories. The participants' use of timelines to draw significant events from their lives may facilitate their construction of the characteristics of their life stories (Adriansen, 2012).

Furthermore, 'the idea of reflexivity is the ability to break away from a fixed frame of reference and to look at what is not capable of saying' (Alvesson & Sköldberg, 2009, p.270). In this regard, I sought to be open to discovering what my role is as a researcher, a process that arose through carrying out the research. Therefore, my position as a qualitative researcher is simultaneously one of being a constructing subject and a constructed object. As a direct consequence of undertaking the research, I came to acknowledge how my own preconceptions and assumptions may influence my role as a researcher. At the point of analysis, I sought to place my preconceptions and expectations aside to undertake the analysis process in a less biased manner, through concentrating on the participants' language and symbols. Furthermore, the participants were asked to confirm the accuracy of my understandings of their life story. Effectively performing this process places the trustworthiness of the research at stake. Thus, the trustworthiness was not something that was imposed from the outside, rather it was linked to the participants (including myself).

#### 4.9: Ethical Considerations

For qualitative researchers who extensively participate in all aspects of the research process, they themselves are a variable contributing to the research data's construction (Brinkmann & Kvale, 2005). Therefore, it is crucial for them to consider not just their own conduct but also the environment wherein the research occurs. Researchers have responsibilities towards their participants, with their research designs needing to both communicate and represent their participants effectively. This study may involve the discussion of sensitive topics, meaning that both the interactional style and the life story topic contents must comprehensively account for participants' rights and needs (Mason, 2002). To fulfil this requirement, I underpinned this research conduct with Kvale's

'Moral Issues of Interviewing' (2007). This stipulates that 'caring is committed ethics', namely that a sustained professional distance is not always conducive to participant well-being. Rapport is advantageous in terms of the participant's experience of the research process, while data of superior quality is a likely byproduct. Additionally, the project has adhered to agreed institute procedures and has been approved by The University of Reading Research Ethics Committee. BERA guidelines (BERA, 2018; Rich, 2018) were also adhered to, thus guaranteeing that the research-practice has positioned reason, outcomes, consent, personality, connections, confidentiality and security as central to the research process.

Therefore, the ethical criteria included:

- Informed consent and the right to withdraw;
- Privacy and data storage;
- Avoidance of harm to participants;
- Duty of care;
- Power issues.

## 4.9.1: Informed Consent and Right to Withdraw

Firstly, in accordance with BERA ethical guidelines (BERA, 2018) and given the likelihood that the participant discussions concentrated on subjects of a personal nature (for example the emotions linked to stuttering, stuttering's negative social experiences and so forth), the participants were informed that this would possibly be the case prior to their participation. I clearly stipulated the voluntary nature of their participation, that they were free to withdraw from the research at any point, as well as the situation whereby providing informed consent does not invalidate these rights. The process of gaining informed consent was conducted by email and Snap Chat; participants received a participant information sheet and an informed consent document. This method ensured that the participants had sufficient time to consider their involvement, with me encouraging them to give their decision due consideration. Moreover, I ensured that the prospective participants had sufficient opportunity to ask any questions that they might have had (see Appendix F, page 290: Participant Information Sheet and Consent Form).

# 4.9.2: Privacy and Data Storage

Secondly, confidentiality means that participants' identities are not revealed during the research (Silverman, 2017; BERA, 2018; Rich, 2018). I emphasised to participants that their identities would remain unknown to anyone but myself, therefore they would remain anonymous. I labelled each participant using a pseudonym of the participant's choice. However, presenting some of the demographic data of the participants, for example age and gender, was essential during the reporting process. Nevertheless, no person-identifiable data were reported. All person-identifiable data, for instance data related to the companies where they work, will be destroyed immediately following submission of the final thesis.

Regarding trust and data storage, it was my responsibility to interact with the participants in a reasonable and ethical manner. As researchers play a fundamental role in the data obtainment and recording process, it is essential that their conduct is both transparent and precise (BARA, 2018). Unprofessional or coercive conduct, for example altering the data or manipulating the environment or circumstances to this effect, must never be engaged in. Therefore, the participants were fully informed about how their stories would be recorded and saved. Furthermore, it was significant that the participants understand how their data will be used, as well as why it was being sought. Additionally, the participants participated in certain aspect of the data analysis, as a means of ensuring that the data were not interpreted in a manner that differed from the participants' intended meanings.

# 4.9.3: Avoidance of Harm to Participants

Storytelling and recording processes involve a certain degree of general stress, which may be exacerbated among PWS because of their speech difficulties. Therefore, in this study the participants were provided with a choice of whether to provide an oral or written life story. Both the oral and written approaches enable PWS to voice their experiences. They have experiences and knowledge that non-stutterers do not, which positions their sentiments as uniquely valuable to a researcher. As Crichton and Childs (2005) explain, the use of the online methods (and listening their real voices and reading their written stories) can give voice to interviewees and elicit their views and perspectives. The participants were informed that their involvement remains under their control; for example, they could choose to write or draw (as opposed to verbalise) their responses, or

make audio recordings in a location and at a pace of their own choosing. They were also encouraged to use pictures and/or photographs to support their responses.

Additionally, there was a likelihood that certain participants might find it difficult to speak openly about their stuttering experience, because they struggled to express the emotional impact, and/or they preferred not to discuss the issue. In such circumstances, my role was to support them to say what they wanted to say, while avoiding pushing them to share knowledge that they might feel uncomfortable with disclosing or discussing.

## **4.9.4: Duty of Care**

Given the fact that storytelling may be challenging for some PWS, I had a duty of care to all of the participants. Ultimately, their emotional and physical well-being was my ethical and moral responsibility. To mitigate the risk of emotional distress, I provided participants with a copy of the life story topic, then asked them to perform their life stories without time constraints. This provided them with sufficient time to consider both the topics and the information that they wanted to share. I understood that asking the PWS to talk may have resulted in them feeling stressed or uncomfortable. Therefore, all participants were informed that they could opt to type or draw their answers rather than speaking. I did not interrupt their responses, while clarification was only sought once the participant had completed the process of providing their written or oral life stories, or speech turn (in the case of the Skype interview) that related to a particular story or event. When necessary, I ensured that my follow up questions were neutral, because questions communicating a sense of judgement or criticism had a likelihood of causing harm. Furthermore, participants were permitted to decline answering questions that they did not wish to answer.

In the event that any participant required emotional support, this was provided through ensuring that participants had somebody to talk, while also encouraging them to call the public government organisation that has been established in order to support people who require advice in dealing with personal issues. This information and relevant contact information was provided as part of the 'participant information sheet'. Additionally, I made contact with the participant again post-interview (and post-receiving their written and oral life stories), so as to check on their experience and well-being. They were made

aware of my availability to respond to any questions and issues, with the information regarding the support organisations again being reiterated.

### 4.9.5: Power Issues

I was cognisant that I must act sensitively regarding the participants' personal differences in terms of verbal abilities and social aptitude, including any variations in their conversational proficiency. Consequently, the participants were offered all of the support that they required to ensure that each of them had the opportunity to participate in sharing their life stories to the utmost of their abilities. The research data collection approach was intended to establish a comfortable environment wherein participants were able to share their views as part of a relaxed conversation. Ultimately, these issues did not arise because:

- All participants selected their preferred approach for sharing their life story;
- All participants were partially involved in the data's interpretation;
- The manner in which participants were recruited diminished my power, given that I did not select them. Rather, the participants contacted me and volunteered their participation in this study;
- The participants were asked one open question to initiate their relation of their life stories, as a means of facilitating their free reconstruction of their stories. Therefore, my control over the data was restricted further;
- Conducting the written and oral life story method online potentially empowers the participants, because they gained the ability to regulate their own environment (Hanna, 2012). They could write or voice record their stories comfortably in their own homes, while they also did not have to respond immediately to my follow up questions, instead elaborating on their answers in their own time.

Despite the significance of acknowledging that no qualitative interview is free of bias or the researcher's influence, through training and practice—for example interview-approach training (Smith, Flowers, & Larkin, 2009)—mitigation of their more serious effects has proven effective. When addressing sensitive topics, for example stuttering, researchers must give prior consideration to how they will respond to any participant's distress, disclosures and so forth in an appropriate and supportive manner.

# 4.10: Summary of the Research Methodology

This section presents a summary of the main methodological aspects of the current research. As a means of answering the research questions, a life story method was employed to collect individuals' stories of their stuttering experience. This study has adopted a qualitative approach informed by the Social Relational Model of Disability (SRMD) (Reindal, 2008; Thomas, 2004), combined with Symbolic Interactionism (Plummer, 1990). The SRMD is adopted to understand the role of the interaction between intrapersonal elements and external factors in determining stuttering's effect on one's life. Meanwhile, the Symbolic Interactionism approach (Plummer, 1990) was applied in order to interpret the meanings underpinning the participants' life stories.

This study is informed by sixteen life stories, with eight men and eight women involved, all of whom are Saudi Arabian adults who stutter. The participants used visual and written or narrated methods to reconstruct their life stories of being PWS. These visual materials were analysed by describing each one, followed by a connection of them to their wider life stories. The written and narrated life stories were initially reconstructed in chronological order via life history analysis and procedures. Subsequently, the emerging themes were identified through applying life story analysis (Thematic Analysis), involving an assessment of the life stories as reconstructed by the participants. Following this, the meanings underpinning the participants' life stories were appraised in relation to the SRMD. Prospective issues regarding researcher subjectivity were mitigated by partially engaging the interviewees in the analytical procedures, namely the interpretation and clarification of their stories' meanings. Also, the research process complies with the BERA guidelines (BERA, 2018), as well as having been approved by The University of Reading Research Ethics Committee.

The data analysis findings are presented in Chapters 5 and 6. Chapter 5 represents PWS' lived experiences, thus it concerns the events and stories that occurred during their everyday lives and which contributed to shaping their stuttering experiences. Meanwhile, Chapter 6 represents PWS' life stories as narrated by the participants, thus aiming to investigate the manner in which PWS derive meanings from their broader life stories. Accordingly, rather than narrowing the focus on to the lived experience of stuttering, Chapter 6 presents the broader vista of these experiences, which subsequently can support

PWS with having their voices listened to and conveying what they want others to know about their experiences.

# Chapter 5: Findings Part 1: How do PWS Perceive their Lived Experience of Stuttering?

This chapter presents the findings in accordance with the themes generated from the participants' life storis, thus aiming to illuminate the events and stories that participants confronted since their childhood and throughout their lives. These events occurred during their social interactions, at home, school and in social contexts, all of which played a role in shaping their stuttering experiences. In this chapter and the subsequent chapter (Chapter 6), the findings are generally presented with very limited reference to the literature, in order to maintain the focus strictly on the participants' voices. However, a more theorised discussion involving the literature will be presented in Chapter 7. Participants' background information is re-presented in Table 5.1 as a point of reference for the reader.

Table 5.1: Study Participants

Pseudonym	Gender	Age (Years)	Methods of conducting the life
			story
Alia	Female	18	Written
Haifa	Female	19	Skype interview
Yasser	Male	19	Written
Fahad	Male	20	Written
Omer	Male	21	Voice messages
Sarah	Female	21	Written
Fajer	Female	21	Voice messages
Baraa	Male	23	Written
Tara	Female	23	Voice messages
Maha	Female	25	Voice messages
Ali	Male	32	Voice messages
Abu Abdullah	Male	34	Written
Al-Anood	Female	34	Written
Mohammed	Male	40	Written
Kholod	Female	48	Written
Rakan	Male	57	Voice messages

The results generated from the Thematic Analysis of the participants' life stories are presented in Table 5.2.

Table 5.2: Findings of the Lived Experience of Stuttering

Table 5.2: Findings of the Lived Experience Themes	Subthemes
Stuttering: The Concept and its Causes	PWS' Definitions of the Stutter;
	Perceived Causes of Stuttering.
The Recognition of the Stutter as a Result	
of Social Interaction	
The Role of Family in Stuttering	Positive Family Support;
Experience	Lack of Family Support.
The Impact of Stuttering on Educational	Perceived School Support;
Life	School Insufficient Assistance;
	School Positive Support;
	Perceived Teachers' Feedback.
The Impact of Stuttering on Professional	
Life and Career Choices	
David Dieg ti da da da	Digg. 11
Participants' Difficulties with Social	Difficulties in Introducing Names and
Interaction	Starting Conversations;
	Participants' Perceptions of Listeners'
	Reactions;
	Bullying;
	The Role of Societal Awareness on
	Stuttering Experience;
	The Impact of Social interactions at
	Teenagers; The Effect of Stuttering on Friendship.
Avoidance	Avoidance of Negative Reactions;
Avoidance	Avoidance of Negative Reactions,  Avoidance to Prevent Being Judged by
	Families;
	Avoid Stressful Situations, and Methods
	of Avoidance;
	Perceived Avoidance as a Problem in
	Different Context.
The Impact of Stuttering on Sense of Self	Elements Led to Low Self-Concept;
	Self-Concept as Affected by Age and
	Social Expectations.
Treatment Limitations	

## **5.1: Stuttering: The Concept and its Causes**

This section is divided into two parts: one concerns the personal definitions of stuttering, while the second relates to the perceived causes of stuttering.

# **5.1.1: Personal Definitions of Stuttering**

Participants defined and described their stutter using different words, although most participants adopted language related to difficult experiences. The participants' descriptions of stuttering were grouped into four strands of interpretation: as a disfluency

and block; a psychological and physical condition; a mystery; a part of self-identity (Table 5.3).

Table 5.3: Personal Definitions of Stuttering

Participant	Disfluency and block hindering their self-expression	Psychological and physical condition	Mystery	A part of self-identity
Fahad	✓			
Ali	✓			
Mohammed	✓			
Rakan	✓			
Alia	✓			
Baraa	✓			
Omer	✓			
Yasser	✓	✓		
Fajer		✓		
Sarah		✓		
Haifa		✓		
Al-Anood		✓		
Kholod		✓	✓	
Maha			✓	
Tara	✓			<b>✓</b>

The description of stuttering as a **disfluency and block hindering their self-expression**, was how nine participants described it. In terms of the presentation of stuttering symptoms Fahad, Ali, Mohammed, Rakan, Tara, Alia, Baraa, Omer and Yasser. Fahad, Ali, Mohammed, and Rakan explicated their stuttering as being a disfluency hindering their self-expression. For example, Rakan stated that,

'stuttering is a lack of ability to speak continually',

#### while Mohammed said it is:

'a stoppage in speech disabling the person saying what they want to say'.

Thus, the participants related their stuttering to being unable to talk as a result of this block, irrespective of the fact they knew what they wanted to say.

Meanwhile, Alia, Baraa, Omer and Yasser used words such as 'block', 'rocks' and 'wall', which describes their feeling of stuttering. Alia, for example, described the moment of stuttering as 'confined breaths', explaining the feeling of stuttering as having rocks in her mouth:

'Confined breaths, words that are hard in my mouth, like stones, are difficult to take out. A word is dead, and it stands in the way of other words.'

Similarly, Yasser's social communication difficulties were interlinked with his sense of breathing difficulties, deriving from stuttering creating a block or 'big wall':

'An obstacle to interaction with the wider community and indeed my own family is posed by stuttering, which I can describe most effectively as a big wall [...] I feel I am unable to breathe while talking because of the speech block'

The language that participants adopted to describe their moments of stuttering present the meaning of challenging and difficult experiences confronted by them during instances of stuttering. 'block', 'rocks', 'stones' and 'dead word' are terminology conveying words as heavy inanimate objects, unable to be moved and unresponsive to attempts to do so. Additionally, participants' daily social engagement and communication has been markedly affected by stuttering, as Yasser clarified. A family and wider societal barrier is posed by the 'disfluency' and 'big wall' of stuttering.

A further example is from participant Tara who indicated that she is still unable to overcome the painful and difficult feelings that she experiences every time she is unable to say a word that she wants to. Tara emphasised that, for her, the most challenging aspect of her stuttering experience relates to the block on her speech:

'The thing that really affects me most, and what I cannot transcend, is the feeling of pain that occurs when I want to say something, yet I am unable.'

She explained that such feelings possibly stem from her experience of confronting these speech blocks during social situations. For instance, during her oral examination, Tara explained her inability to reply to her teachers' questions, despite being aware of the correct answers. Therefore, stuttering was identified as preventing these participants from engaging in social interactions and conversations.

Stuttering is viewed as a **psychological and physical problem**, as noted by six participants—Fajer, Sarah, Haifa, Al-Anood, Kholod and Yasser—who explained that it hindered their social engagement. For example, Fajer related how 'stuttering is a psychological condition that may have been resulted due being shocked', while Sarah remarked that 'stuttering is a psychological condition or physical health issues, and it disables the person from the inclusion with their societies'. Moreover, certain participants, such as Al-Anood and Kholod, used the word 'disorder' in relation to their

stutter. For example, Al-Anood explained that 'stuttering is a speech disorder and also a psychological disorder'. Accordingly, the data indicates that certain participants perceived their stuttering as a condition with a psychological or physical basis.

Furthermore, stuttering is a **mystery**, as two participants Maha and Kholod suggested. Both of them defined their stutter as a 'mystery' due to being unable to explain why it occurred. Maha noted: 'I cannot define stuttering (it) is a mystery', while Kholod pondered: 'I do not know, it is a strange disorder, I do not know when and why it appears'. Maha and Kholod initiated their life stories by considering stuttering as a concept and defining it, indicating that they found their stuttering a mystery.

Stuttering was also perceived as **a part of self-identity**, although just one participant described having accepted her stuttering positively in this manner. Participant Tara did not define her stutter, because she believed stuttering to be a part of her self-identity: 'Stuttering is just a stutter, I live with it and it is just a stutter, it is a part of my identity'. Therefore, there were no specific words that Tara adopted to describe her stutter, given that she believed it was indistinguishable from her personality.

In summary, the participants defined their stutter through words that described how they feel when stuttering, which included the speech and social challenges they experienced. Consequently, their definition of stuttering may be summarised as the disfluency and block in the speech which makes them feel unable to express themselves and communicate in their society.

## **5.1.2: Perceived Causes of Stuttering**

Five participants related stories about the variables and events they thought might have initiated their stuttering. For these individuals, these events related to difficult childhood experiences, being in a scary situation, as well as anxieties generated from being at school and in other social contexts (Table 5.4).

Table 5.4: Perceived Causes of Stuttering

Participant	Difficult childhood	Scary	fears of oral	Psychological
	experiences	experience	examination	aspects
Fajer	✓			
Yasser		✓		
Omar		✓		
Fahad			✓	
Al-Anood				✓
Alia				✓

**Difficult childhood experience** was perceived as a cause of stuttering. For example, participant Fajer related that her mother told her she used to be particularly attached to her milk bottle, with Fajer suggesting that the manner in which her milk bottle was taken away was potentially connected to her stuttering:

'My mom told me that I was addicted to the milk bottle, however, she took it away from me in the wrong way and I reacted adversely. I continued to drink from the milk bottle until I entered second grade of primary school, which was abnormal.'

Fajer stuttered since her early childhood; although she explained that as she was trying to recall her stuttering's cause, she could not point to any harrowing events that might have been responsible. Therefore, she attributed the cause of her stuttering to the milk bottle story.

For others, stuttering was perceived as stemming from and being caused by adverse childhood experiences, for example fears. Yasser, at seven years of age, had a **scary experience** which he believed might have triggered his stuttering:

'My stuttering began when I was a child because of a scary experience, after which I began stuttering. When I was seven or eight years of age, I stayed in a hotel with my relatives and cousins. My cousins' suite was connected to my family's suite via a corridor, which I regularly ran down while going often between the two suites. However, at one point a white-haired elderly woman with a stick, who looked very intimidating, appeared in the corridor. Having frozen for some time, I ran to my cousins' suite, where I felt very cold and was shivering from fear.'

Understanding one's development of stuttering as being a consequence of a frightening or intimidating experience, could explain Yasser's association of this experience with the emergence of his stutter. Although Yasser's stuttering's cause may not have definitely been this experience, as Yasser acknowledged, the connection he made between this

frightening recollection and the hesitation and other aspects of his stuttering experience is important for Yasser.

Likewise, participant Omer attributed the triggering of his stutter to a frightening event of violence that he witnessed during second grade at primary school:

'I started to stutter while in second grade of primary school. Before that, between kindergarten and the first year of primary school, I used to study at a fee-paid school. For my second year I went to a state school, where I saw a teacher punching a student. This caused my stutter and made me hate the school.'

Omer's recollection of this event profoundly affected him, to the extent he considered it to have caused his stuttering. A further point raised during Omer's narrative concerns the comparison between a fee-paying school and state school, as he explained it was at the latter where he initially witnessed a violent incident. Fee-paying schools and no-fee state schools both comprise the Saudi Arabian education system. Fee-paying schools are guided by parents' funding, resulting in students typically being more empowered in such schools (Alahmari, & Kyei-Blankson, 2018), as well as being at less risk of suffering mistreatment at the hands of school staff. Therefore, the type of school may have shaped Omer's stuttering experience while in education.

Fahad noted that he began stuttering during the second grade of primary school, which he attributes to his **fears of an oral examination**, and being punched:

'The stutter started when I was in the second grade of primary school. A teacher was holding an oral examination [...] I made a mistake and he criticised me harshly. I became stressed and I started to stutter.'

Fahad provided an in-depth narration of this event, divulging both his feelings and the teacher's reaction, thus indicating this event's significance within his life story. He said that this was not simply due to him locating this event as his stuttering's cause, it is also due to it potentially representing the point at which his life story with stuttering began.

Moreover, stuttering severity was connected to **psychological aspects**. Participant Al-Anood related her view on how her stuttering severity changes in accordance with her psychological status and feelings:

'At university I was very happy, the level of my stuttering sometimes goes up and sometimes dawn due to my psychological status. When I am sad or upset it becomes severer'.

Consequently, Al-Anood observed that her stuttering's severity is linked with her feelings. This observation potentially derives from her belief that her stuttering is a psychological issue. Similarly, Alia explained that her stuttering severity was changeable, depending on the particular context and words being used. For example, she has no stutter at all if she is alone, whereas she stutters considerably in front of other people:

'I read while I am alone. I can read an entire book without stuttering on any word. Yet when I read in front of another person, I become unable to say two words together'.

Thus, the participants who discussed their perceived underlying reasons for their stuttering typically focused on challenging and disturbing events that they experienced. They perceived that their stuttering stemmed from these causes rather than being a physical health problem.

# 5.2: The Recognition of the Stutter as a Result of Social Interaction

Certain participants indicated their recognition that they stuttered as a consequence of challenges confronted in social settings and schools. Maha, Haifa, Al-Anood, Kholod and Rakan recalled that they did not recognise that they stuttered until school age when they faced social difficulties and negative comments (Table 5.5). The point at which they said they recognised their stuttering was between the age of 6 and 12.

Table 5.5: The Recognition of the Stutter

Participants	Due to difficulties	Due to social	Due to others'
	in a reading task	interaction in	negative reactions
		school	
Maha	✓		
Haifa		✓	
Al-Anood			✓
Kholod			✓
Rakan			✓

Participant Maha related how her family told her she was a fluent and intelligent child, yet she started stuttering just before school age. Maha clarified that despite her stutter

emerging when aged five or six, it was very mild and she was unaware that she was stuttering. Subsequently, during fifth grade of primary school, Maha started realising that her stuttering was an issue, obstructing her completion of a **reading task:** 

'I was told by my family that I began walking and speaking earlier than other children of my age [...] I mean my mental ability was very good [...] I began to stutter when I was five or six years old, but I did not even pay attention to it. When I was in grade five at primary school I started focusing more on my stuttering. [...] I was asked by the teacher to read and I was shaking [...] I stuttered and I cried, then the teacher asked me to sit-down. Neither she nor my peers commented on this, but I cannot forget this story.'

Maha constructed her childhood knowledge and understanding from the information related to her by her family. This indicates the role that family social interaction played in shaping Maha's personal understanding of her childhood. Thus, she was unable to personally recollect this early childhood period of her life story, completing her picture of the time through information derived from relatives.

Participant Haifa explained how, despite believing she had been born with a stutter, she only realised she had a problem at the age of eight, following **social interactions** at school where other people emphasised her differences:

'I feel that my stuttering began with me once I learnt the language. I did not feel the problem before [...] However, when I started interacting with people, I felt that there is something, even if I felt that my stuttering is normal, it may be that other people do not see it as normal.'

The following quotation concerns an event that Haifa was involved in while in the second grade of primary school, aged eight, which made her recognise her stutter. Haifa received some negative feedback from her friends. Nevertheless, it is significant that Haifa's friend was retorting to Haifa's initial negative comments to her:

'My friend said, 'you are the one who has no money, if you had money you would treat yourself. It was then that I became sensitive about my stuttering and I felt it is a problem'.

Subsequently, Haifa identified her stutter as a problem and began focusing on it in this way due to experiencing negative words from one of her classmates. After which she recognised that she had a speech impediment that needed to be treated.

Al-Anood related how she started stuttering at six years of age, prior to beginning school. She acknowledged that she stuttered due to **others' negative reactions** to her speech:

'I knew that I had a problem as a child because people laughed at me when I spoke and stuttered. I knew that it was a speech disturbance.'

Accordingly, Al-Anood recognised the problem of her stutter as a result of it being reflected in her social interactions, with social feedback and reactions making Al-Anood realise that she was different to other people of her age.

Likewise, participant Kholod said that she was not concerned about her stuttering until she entered secondary school. Kholod pointed out that during childhood, she played contentedly with peers, while her teachers were cautious to avoid drawing Kholod's attention to her stutter. However, this changed during secondary school, with Kholod's peers emphasising her stutter and persecuting her for it, while her teachers made no efforts to protect her. People began asking questions about her stutter driven by numerous assumptions; while at senior school, her stuttering meant she experienced **negative reactions from others**:

'I did not feel the problem of my stutter until secondary school [...] people kept on asking me questions like, 'Why do you speak like you do?'

Once people pointed her stutter out and persecuted her as a result, Kholod states she developed an awareness of her stuttering. Kholod's narrative evidently shows that a negative social environment, wherein people concentrate on one another's differences, in addition to the lack of social support, can create further social barriers for individuals who then develop greater conscious of these differences and are affected by them.

Similarly, Rakan recalled his realisation that he stuttered as being an outcome of other's negative reactions and teasing, both from his peers and teachers, during fifth or sixth grade of primary school, meaning he was aged 11 or 12:

'I recognised my stutter when I was in about the fifth or sixth year of elementary school. I suffered because of some of my friends. For example, if I repeated a letter, they would repeat it like I did. I remember a word that I still have in my mind, the

word 'sakin' [knife]. I remember saying, 's s s sakin', then a person teased me. I also remember when I returned home from school, I felt heartache and annoyance because of what occurred at school.'

Rakan initiated his life story at this point, essentially the time at which he became aware of his stuttering aged 11. Thus, regardless of his uncertainty whether his stuttering began at birth or subsequently, he recalled his first realisation that he stuttered.

Therefore, Rakan, and most of the participants, began by relating their stuttering life story from the point they felt the problem, meaning that their stuttering experience started at the point which they recognised their stuttering. In this regard, stuttering may have led to no detrimental consequences for them prior to their realisation that they did in fact stutter, which was the point at which they confronted negative feedback and teasing during their social interactions at school. Facing difficulties in school is already commented on the literature (Ellis & Hartlep, 2017; Daniels, Gabel, & Hughes, 2012), but there has been very little written about the fact that starting school is related to perceiving the stutter as a problem. Findings related to the role of school memories on the experience of stuttering will be further discussed in Chapter 7.

# 5.3: The Role of Family in Stuttering Experience

Participants noted the conflict in their parents' attitudes towards their stuttering. The majority of the participants who discussed their parents' attitudes and role, noted they had supportive mothers with positive attitudes towards their stuttering, accepting their condition and encouraging them to visit speech therapists. Contrastingly, their fathers were perceived as being unsupportive, expressing negative attitudes towards them and their stuttering, while rejecting the idea of visiting speech therapists. This section is divided into two main themes: positive family support and lack of family support.

# **5.3.1: Positive Family Support**

Participants who considered their families to be supportive attributed this to four principal variables: having a comfortable home environment; supportive mothers; encouragement from their mothers to receive early intervention; and mother's acceptance (Table 5.6).

Table 5.6: Kind of Positive Family Support

<b>Participants</b>	Comfortable	Supportive	Mother's assessment	Mother's
	home	mothers	to early intervention	acceptance
	environment			
Omer	✓			
Sarah		✓		
Tara		✓		
Alia	_		✓	
Yasser				<b>√</b>

Participant Omer indicated that having a **comfortable home environment** enhanced his stuttering experience. He clarified how his family provided him with the support he required. He noted that he could converse openly at home, without needing to hide his stuttering; if he spoke and stuttered around family members, they would wait for him to complete his sentence:

'At home, I felt comfortable stuttering in front of my family. They are aware of my stuttering, and even if I stutter, they are happy just to wait for me until I finish my sentence.'

Omer's narrative of his home situation conveys how, given that he did not attempt to hide his stuttering from his family, his stress level declined because he felt secure and comfortable at home.

Whereas Sarah and Tara indicated that they had **supportive mothers**. Sarah and Tara recalled how they did not suffer at home because they had positive relationship with their mothers which provided them with the support they needed. Although Sarah state that she was not from a well-educated family background. Sarah emphasised her mother's supportive nature, assisting her with overcoming the detrimental effects of her school experience:

'I like to tell my mother about everything. For example, I would say, "mom, today I couldn't read, and my classmate laughed at me" She used to tell me not to think about this because she is just jealous'.

Tara confirmed that her mother continued supporting her throughout her life. For example, when Tara confronted academic difficulties after her mother stopped working in the school she attended, her mother endeavoured in encouraging her class participation, telling her not to be ashamed of her stutter:

'I feel that my mother had an influence on me the entire time. For that reason, I am not ashamed of stuttering'.

Tara said that she appreciated her mother's support based on the way in which she discussed her important role, from childhood until Tara's present life stage. Indeed, Sarah and Tara's mothers' positive support proved to be a significant dynamic that affected and smoothed their stuttering experience. Furthermore, Tara stressed her mother's considerable role in encouraging her effective stuttering management and coping mechanisms, including her ability to avoid feelings of shame.

Alia also suggested that her mother provided support, constantly **assisting her to early intervention** and attempting to facilitate her life. Despite her father remaining unconvinced that Alia required treatment, her mother searched for treatment for Alia's stutter:

'My mom was always encouraging me and she was the one who took me to the speech therapist. She facilitated everything for me, God protect her. The reason why I did not treat my stuttering earlier during my childhood was that my dad thought I did not require treatment because my stuttering would disappear as I grew up.'

Despite her parents' divergent perspectives, regarding Alia's speech therapy requirement, whether their attitude to Alia's stuttering was positive or negative is not necessarily indicated. Ultimately, Alia appreciated her mother's efforts to treat her stuttering, with Alia's narrative indicating that she wished she had received treatment for her stutter earlier.

Accordingly, participants' positive perceptions of their families' role were reconstructed from residing in a safe home environment where it was unnecessary for them to hide their stutter, while also having parents who accepted them and provided the required assistance. Notably, this data showed that participants appreciated the moral support provided by their families, through acceptance and their family members' willingness to listen.

# 5.3.2: Lack of Family Support

Strong family support was not the case for all. Participants who related their families lack of support for them explained how: they had received negative feedback from their parents and siblings; received insufficient assistance from them; were raised by old and

uneducated parents; endured domestic violence; and had parents who held negative attitudes towards early intervention (Table 5.7).

Table 5.7: Family Lack of Support

Participants	Parents and siblings' negative comments	Insufficient family support	Raised by old and uneducated parents	Domestic violence	Parents negative attitudes towards early intervention
Sarah	✓				<b>✓</b>
Yasser	✓				
Maha	✓			✓	
Ali		✓			
Mohammed			<b>\</b>		
Abu- Abdullah			<b>✓</b>		
Baraa					✓
Fahad					<b>√</b>

**Negative comments from parents and siblings:** Sarah believed her father and sisters' **comments** and recommendations to seek treatment were unhelpful, as they diminished her self-confidence:

'However, when I was a teenager, my dad and sisters began focusing on my speech, saying 'take a breath', 'talk slowly' and things like this. So I started to avoid engaging in conversations with them. I needed more acceptance from my family.'

Sarah conveyed a varied family experience, receiving positive encouragement from her mother that enhanced her self-confidence while finding her father's and sisters' comments about her stuttering patronising, resulting in her avoiding interaction with them. This potentially emphasises the significance of people listening to *what* an individual with a stutter is saying, rather than *how* they are saying it.

Similarly, participant Yasser noted that his stuttering was to a certain extent perceived unfavourably by his father, contrasting with the greater understanding expressed by Yasser's mother. His father's inability to identify a reason for Yasser's stuttering, alongside his displeasure that it was known by others in the community, resulted in his father telling Yasser to control himself. More recently, Yasser ceased receiving such remarks from his father, although Yasser's sense of displeasure remains apparent from his comments:

'When at home, my dad regularly used to remark: 'nobody else stutters in our family, you don't have an issue. Other people will talk about us negatively, why are your stuttering like this?' and other comments. My dad appeared annoyed and upset. He no longer makes comments to me, although his unhappiness is clear. However, my mum accepts me for who I am.'

Yasser's parents presented varying attitudes towards him but Yasser has reached some personal understanding of his parents' variable toleration of his stuttering. Nevertheless, Yasser's father's negative attitude may have been linked to his anxiety regarding the judgements of others in society.

Participant Maha discussed the effect of her siblings' feedback on her experience. Maha has eight siblings, six older than her and two younger brothers. She elaborated on how she has good and normal relationships with the majority of her siblings, although one of her older brothers has mistreated her since childhood:

'My relationship with my siblings is normal, although my relationship with one of my older brothers is very bad. He has a very negative personality generally, he does not make me feel like he is a brother [...] Once I was discussing with my sister and practicing a speech technique for reducing my stutter, when my brother came over and said 'talk properly, or I will slap you in the face.' I did not answer back.'

Maha observed that such negative feedback from her unsupportive brother profoundly affected her relationship with him, as he never acted like a supportive brother. Notably, Maha discussed her negative relationship with one brother, yet made no in-depth explanation of the relationship with her other brothers who possibly had more positive attitudes.

Regarding **insufficient family support**, participant Ali perceived the kind of support offered by his family during his childhood as inadequate. Ali's family interactions and his interpretation of his family's response to his stuttering while he was a child, in terms of not encouraging him to talk during social gatherings, exacerbated his low self-esteem and made him feel he was unable to engage with people:

'Although, my family attempted to provide me with support, as they were considering this as support it often backfired. For example, during social events, they did not encourage me to participate in conversations. They wanted to protect me from shame and embarrassment. I considered their attitude condescending,

which negatively affected me, although I was well aware of the fact that they wanted to help me.'

Despite Ali's unhappiness with his family's choices, his family's actions are not necessarily categorically negative, because they may have wanted to avoid placing pressure on their child by forcing him to engage and converse in social contexts.

Being raised by old and uneducated parents: Mohammed and Abu-Abdullah indicated that they received no support from their families, due to having old and uneducated parents. Mohammed, as the youngest child of elderly parents, saw these circumstances as affecting his childhood experiences, because he felt isolated and unsupported. As well as being the youngest child in his family, all of Mohammed's brothers were old enough to be employed, because there was a marked age gap between them. This created a distance between Mohammed and his brothers, resulting in him lacking the support he could have expected from his brothers when experiencing bullying at school or on the streets. Ultimately, Mohammed stated that he had nobody who could support him or even complain to:

'I lived alone at home with my parents who were old. All of my brothers had left the city for work. Thus, I received very little support at home, nor was there anyone to complain to when I faced problems at school or on the street.'

Mohammed's narrative indicated that he blamed his situation on being the youngest child and the only one remaining with his elderly parents.

Participant Abu-Abdullah attributed the dearth of parental support he received during childhood to their educational level. Abu-Abdullah clarified that he received no support from his family because his mother received no schooling and his father's educational level did not surpass primary school level:

'Indeed, I am talking about the year 1992, and at that time my family was unaware of this thing, because my mother is illiterate, and my father reached only his fifth primary education level'.

Abu-Abdullah connected the insufficient support and awareness of his parents to their low education level. He detailed how, during his childhood, his parents possessed insufficient education to permit their development of greater awareness of Abu-Abdullah's stuttering problem, thus being able to provide him with requisite support.

Regarding **Domestic Violence**, Maha noted that her father was violent during her childhood, while she also had a negative relationship with her mother who played a limited role, as she stated in her life story. Maha explained that she was subjected to both physical and verbal domestic violence by her **father**, involving emotional and psychological abuse. Moreover, she witnessed her father's abuse of her mother:

'I cannot forget when I was 4 or 5 years old and he was shouting at my mom.'
She elaborated further:

'I feel my father is criticising me all of the time [...] one time he told my younger brother 'you are small but you can speak very well and there are other people are in secondary school and they cannot read'. He was pointing at me'.

#### Furthermore, Maha related how:

'He hit me with a stick very hard until I wet myself.'

The manner in which Maha conducted her life story showed that she was tremendously affected by domestic violence. In beginning her life story, Maha discussed her general family circumstances, alongside specifics concerning her damaging relationship with her father (and her older brother as it was mentioned previously). Maha explained that the domestic violence and negative relationship with her father potentially contributed to developing a stutter. She emphasised that physical violence, fear and uncertainty inevitably and detrimentally affected her personality and life.

Being abused by a parent can be a particularly sensitive subject for the participant to disclose information about it. Accordingly, all ethical protocols explained in Chapter 4 have been followed, with participants' well-being prioritised. The participant was aware that she was under no obligation to share her story, yet she felt confident sharing it regardless, while also explaining that this story was from her past rather than now. Thus, despite these stories being particularly harsh and certainly having an effect on her, the participant discussed them in the interview and felt confident narrating them as an aspect of her life story.

Parents' negative attitudes towards early intervention: participants Baraa, Fahad and Sarah explained how their parents' attitudes towards early intervention discouraged parents from taking their children to visit a speech therapist during their childhood. The principal theme shaping Baraa's life story relates to the blame he places on his family for ignoring his childhood stutter. Baraa began his life story by recalling how his stuttering

started, in addition to discussing how his family responded by declining to treat his stuttering. Fundamentally, Baraa blamed his family, suggesting that receiving treatment during his childhood could have enabled him to overcome his stutter by this point:

'At first my family thought that my stuttering would go away by itself, but as time went on, the stuttering increased. I now believe that the main reason for my stuttering is the lack of care from my family, so my stutter continues to this day [...] When I was a child, I didn't understand why my family did not do that [treat his stuttering], instead they just chose to leave it and the thing is over now.'

Baraa emphasised the role that family plays in early childhood intervention to tackle stuttering. Moreover, he cannot understand why his family ignored his stuttering during childhood. This potentially indicating that Baraa continues to consider whether his family made the correct decision and, if they had sought intervention, how he would have perhaps overcome his stuttering. Consequently, this experience is the fundamental component shaping Baraa's life story.

While Participants Fahad and Sarah discussed how their parents' attitudes regarding their treatment needs were shaped by their previous experiences with their siblings, who had stuttered and ultimately overcame it without intervention. Consequently, their families did not encourage Fahad and Sarah to visit a speech therapist. Regardless of Fahad noting his mother's supportiveness, his wider family disagreed with Fahad concerning his treatment requirements. Rather, they believed that he would naturally overcome his stuttering, particularly given that his brother previously stuttered for a short period, yet ultimately overcame it without intervention:

'I told my family about my stutter and that I need to visit a speech therapist, but they did not agree and told me 'it will go away when you get older, like your brother'.

The stuttering did not last long for my brother, yet I did not overcome it.'

Fahad's family opted to discourage him from accessing speech therapy, based on their previous experience with Fahad's brother, who managed to overcome his stuttering without intervention. They might have believed that similarly, Fahad would naturally overcome his stuttering, yet this did not occur. At the time of the research, Fahad was 20 years old and continued to stutter.

Comparably, Sarah explained how her family's perspectives towards her stuttering obstructed her receiving treatment from an early age. Ultimately, her family's perspective

was affected by their previous experience of Sarah's sister, who stuttered for a brief period during childhood, meaning her family deemed Sarah not to require any early intervention. When Sarah did not overcome her stuttering as her family anticipated, her mother offered to take her to a speech therapist. Sarah declined this as a teenager, believing it was too late by then:

'I did not visit the speech therapist when I was younger because my family thought that I would overcome the stuttering once I got older. This is because one of my sisters stuttered when she was a child'.

#### She continued:

'One day my mom said to me, 'our neighbour knows a good speech therapist, shall we visit him?' Yet as any teenager would, I told her I do not need it now and that she should have taken me when I was younger.'

Consequently, Sarah 's treatment journey was limited because her family believed she required no early intervention. They were confident that she would overcome her stuttering just as her sister had done. Ultimately, the difference between the participants and their siblings is a point that may emphasise individuals' particular circumstances in overcoming stuttering, as people are different in the way they overcome or control their stuttering (Plexico et al., 2009b; Isaacs & Swartz, 2020).

In summary, responses regarding the manner in which participants discussed their parents' attitudes towards them and their stuttering has been discussed from the participants' perspectives, in terms of how their parents responded to their speech treatment needs. For example, those participants who deemed their mothers to hold a positive attitude explained how they supported their need to visit a speech therapist. Meanwhile, families' unhelpful feedback, judgments about, as well as overprotection of their children were perceived as conveying insufficient support by certain participants. Moreover, being raised by elderly and uneducated parents was perceived negatively by some participants, given that they associated this with having nobody to support them while facing difficult situations. PWS' perceptions of parental support and their stuttering experience will be further discussed in Chapter 7.

# 5.4: The Impact of Stuttering on Educational Life

The fourth theme explores stuttering and the impact on education. Six participants explained that stuttering had negatively affected their educational life. The majority of

participants indicated that they experienced social interaction difficulties, alongside academic challenges with oral tasks such as reading, oral examination and personations. Nevertheless, just a single participant revealed that they also faced writing challenges, as presented in Table 5.8.

Table 5.8: The Negative Impact of Stuttering on Educational Life

Participants	Deterioration	Classroom oral activities and examinations	Writing difficulties	Others' reactions related to participants' academic difficulties
Alia	✓			
Yasser	✓	✓		
Haifa		✓		✓
Abu-Abdullah		✓	✓	
Fahad		✓		✓
Sarah		✓		✓

Participants Alia and Yasser commented that once they acknowledged how stuttering would potentially affect their future, their school educational and social performance began **deteriorating.** Alia had a contented childhood prior to her stutter emerging. She said that she loved school and participated in school activities, reading activities and the school theatre, while never being absent. Unfortunately, once she began stuttering everything changed for the worse; Alia started skipping school for days, while also being psychologically affected. She was unsure about what her stutter was, albeit having understood from the outset that it separated her from her peers, with her stutter becoming a hindrance during her life:

'I became a stutterer during the fourth grade of primary school, [...] I realised that I was different and this could become a barrier in my life [...] I used to love school, but after my stutter I did not want to go to school and I cried very often.'

Alia started stuttering at a relatively older age, given that she compared her life prior to and following the stutter. Alia conveyed that from the point her stutter developed there was a negative shift in her life.

Yasser saw certain education problems emerge during intermediate school. Greater personal sensitivity to his own stutter arose at intermediate school, whereas his stutter had not weighed so heavily on his mind during primary school. Yasser's educational

performance was affected because in intermediate and high school, he sought to evade participation in class discussions as he became older. Ultimately, Yasser moved to a feepaying school due to his poorer academic results:

'I did not think much about my stutter in primary school, I put my hand up and contributed in class, having a normal experience. However, I began to realise my issues in intermediate school [...] my stutter became particularly serious when I had to make presentations and hand in research at high school. [...] I underachieved. So, I decided to move to fee-paying school.'

In Saudi Arabia, some students who underachieved opted to study in fee-paid institutions (Alahmari, & Kyei-Blankson, 2018). This may be due to fee-paid school students being provided with the additional support and services they require, thus enabling students to be more confident about participating in class activities. Alia and Yasser's narratives show how the timing and age was also significant in their understanding of the stuttering as a problem that can impact their academic and future life. This will be further discussed in chapter seven.

Participants Haifa, Abu-Abdullah, Fahad and Sarah suggested that the academic difficulties they experienced as students, as well as difficulties during **classroom oral activities and examinations**, stemmed from their stuttering.

Two pertinent points concerning academic problems are highlighted by Haifa's life story. The first point regards her problems during oral examinations, when Haifa was unable to speak her answers despite possessing the correct knowledge:

'I have to memorise a part of the 'Quran'. Although I memorised very well, I could not complete the sentences, so it appeared like I had not memorised it, it was a very hard situation'.

The second point relates to the challenges Haifa confronted while participating in class activities. Haifa remarked that despite facing difficulties with contributing to classroom activities, she endeavoured with participating so as to avoid becoming an underachiever, although she felt embarrassed with herself:

'I wanted to be a good student, so I raised my hand when I knew the answer, even if I was unsure whether I would be able to say it or not. Many times, I would stutter a lot [...] and I feel that they would think 'why did she do that to herself?' Now I feel

that yes, I should not have done that, because I was not able to say the answer in a clear and understandable way, I just embarrassed myself.'

Haifa explained how she attempted to transcend the obstacles she faced by pushing herself to participate in school activities, as opposed to perceiving her stutter as an excuse or barrier. Nevertheless, Haifa noted how she simultaneously felt that she exposed herself to problematic situations.

Despite reading challenges being a pervasive difficulty for PWS (Ellis & Hartlep, 2017), participant Abu-Abdullah noted his problems with both reading and **writing**: Abu-Abdullah initiated his life story by stating that he started stuttering during first grade of primary school, with reading and writing both proving difficult:

'In the primary school year 1990-1991, I was a very lazy student [...] I failed [...]

I believe the reason for this failure was that my handwriting was and still is unclear.'

Consequently, Abu-Abdullah faced academic challenges not only with oral components of his work but also with writing activities, which may require direct linkage to his stuttering problem. It is potentially significant that Abu-Abdullah mentioned these writing difficulties, because more research may be necessary for understanding how stuttering possibly affects stutterers' writing skills. It is necessary to consider how stuttering is characterised by various symptoms, including word and letter repetition, as well as disordered letters in words.

**Others' reactions** were also associated with participants' stories of the academic difficulties they faced in school. Fahad and Sarah discussed their feelings that people were gazing at them when they started stuttering in front of the class. The challenges that Fahad confronted during school concerned oral contributions during classroom discussions, for example reading or discussing a subject:

'I feel I want to die when I recall that during the first grade of high school, I was attempting to read in front of the class but I was unable to spell the words. The teacher then asked me to sit down and chose another student to read [...] the students were gazing at me as if I was an awkward person.'

Oral and reading challenges are a typical hindrance for students who stutter, which Fahad also deemed to have caused him social embarrassment and shame.

Participant Sarah identified university as the most challenging aspect of her life experience, particularly because she faced the educational obligation to provide presentations. Furthermore, she had difficulties with receiving others' reactions when they discovered that she stuttered:

'My life at university was the hardest. I remember the first presentation that I did, I prepared myself for two weeks and I was excited. But on the day of my presentation, I was about to begin, yet I couldn't continue. Because the girls did not know me and my stuttering, their reaction was difficult for me.'

Therefore, Sarah's challenging experiences while at university primarily related to the complications of undertaking presentations, alongside her peers' reactions; they were unfamiliar to her, unlike her school classmates who were aware of her stutter.

Stuttering and associated negative feelings such as fears over oral activities, shame and embarrassment, alongside negative reactions and a dearth of support, were considered as detrimentally affecting participants' school life and educational performance. The following section concentrates on participants' discussions of their school support and teachers' feedback.

# **5.4.1: Perceived School Support**

Participants offered their perspectives and viewpoints on the support they had or had not received from school staff, including teachers and educational psychologists. Participants varied with regards to what they deemed to be supportive or not. For example, Sarah's contact with an educational psychologist was not a positive experience, whereas teachers who avoided asking the stuttering student to read were deemed supportive by some individuals, yet unhelpful by others. This section divided school support into three main themes: school's inadequate assistance; school's positive support; and perceived teachers' feedback.

# **5.4.1.1:** Schools' Inadequate Assistance

Particular participants indicated that any form of support emphasising their differences, for example providing them with additional support of excluding them from oral examinations, they viewed as being insufficient. These participants explained that they preferred to be treated just like other students without stutters. Table 5.9 presents the characteristics of school insufficient assistance.

Table 5.9: Characteristics of Schools' Inadequate Assistance

Participants	Lack of assistance	Educational psychologist's intervention	Being treated differently	Unnecessary protection
Ali	✓			
Sarah		✓		
Tara			<b>√</b>	
Haifa				<b>✓</b>

Participant Ali posited that the **lack of assistance** he received while at school had compounded his stutter-related difficulties:

'The school did not provide any support, and neither did the teachers. I was unhappy and frequently returned to asking myself how long I would carry on talking in this way and when would it end?'

The greater the negative social experiences and dearth of support he faced in school, the more that Ali came to perceive his stuttering experience negatively, leading him to ask himself when he would overcome his stutter. Meanwhile, Sarah's narrative regarding her school experience had a negative aspect, as she deemed the **educational psychologist's** intervention as being an embarrassing experience. As in some Saudi Arabian schools, Sarah's had a psychologist whose role was to provide student support when necessary. Nevertheless, Sarah criticised the psychologist's adopted approach to providing her with support to overcome her stuttering. This involved removing her from class in front of her peers for her visit to the sociologist's office:

'I recall that school day as being one of my worst, when the psychologist took my name and asked me questions. And when I returned to the class my classmates were asking me what she had said to me.'

Consequently, despite Sarah's school attempting to provide her with the requisite support, the manner of its delivery was deemed by Sarah to have caused particularly negative school memories.

Participant Tara was dissatisfied about **being treated differently** at school because of her stuttering; she said that she considers PWS as 'normal students' who should not be distinguished from their fellow classmates:

'I explained to my teacher that I wanted to spell the poem in front of my peers. I did not want to be examined individually outside the classroom away from my classmates. I understand that my teacher was trying to be nice to me and to prevent me from being depressed, yet I was crying, crying because I felt that I had a problem, that I was different from other people.'

Tara stated that she disapproved of being offered types of support that made her feel less capable than other students. In this regard, the participants' perceptions of the kind of support they would consider as supportive or unhelpful may be valuable in terms of understanding what could be deemed effective support for a student who stutters. Moreover, it illustrates the importance of seeking the opinions of PWS rather than making assumptions about their needs.

Likewise, participant Haifa discussed home-school interaction's role in providing her with **unnecessary protection** while a student. She perceived such support as unneeded, given that her teachers did not ask her to read in front of the class. Haifa received some support at school once her family contacted them to clarify her stuttering issue, which resulted in her school teachers' improved treatment of her. Even so, they rarely asked Haifa to read, instead simply asking her to write her answer irrespective of whether she felt able to read:

'My family contacted the school [...] one of my brothers called the school leader regarding the stutter [...] afterwards the teacher treated me much better, although she never asked me to read, she would just let me write the answer. Sometimes I wanted to read, I felt I could read, but it was just a feeling.'

Despite Haifa's story potentially raising the significance of home-school interactions, this further highlights the detrimental effects of providing more support than is necessary. For instance, Haifa's teacher's efforts to protect her from embarrassment by not permitting her to read produced certain negative effects obstructed Haifa from attempting to read regardless of her willingness to try. Nevertheless, as will become clear in section 5.4.1.2, certain participants felt it was beneficial to avoid reading aloud in front of their class. Consequently, this expresses individuals' opinions on what is the appropriate type of support that teachers can provide them with, which may differ among students who stutter. Therefore, the reason that some participants such as Tara and Haifa did not

appreciate their teacher's strategy might have been because they were not provided with opportunities to choose whether or not they wanted to read in front of their class.

# **5.4.1.2:** School's Positive Support

Fajer and Yasser had different opinions regarding the type of support they were provided. Fajer was appreciative when one of her teachers treated her the same as her peers. Yasser appreciated the support of those teachers who enabled him to use an alternative examination method, for example writing as opposed to oral tests (Table 5.10)

Table 5.10: School Positive Support

<b>Participants</b>	did not provide her with special	Prevented him from reading aloud
	support	
Fajer	✓	
Yasser		✓

Fajer said that she believes that she has been fortunate due to her supportive friends and teachers, who **did not provide her with special support**. She described how, even when she speaks and stutters badly, they did not present any negative reactions and they did not discuss it. Furthermore, Fajer also appreciated that her teachers treated her just like her peers, because she did not appreciate being treated any different to the majority:

'I really appreciate those people in my life, because they did not make me feel that I am abnormal. [...] my teachers did not make me feel it, they simply treated me like anybody else. I am the kind of person who does not like being treated differently.'

Fajer's position concerning the type of support she appreciates is that it is positive when people do not attempt to offer her any unique services. She wants to be treated to the same as any other person without a stutter. Therefore, she said that she does not approve when people offer or intervene to support her in overcoming her stutter.

Contrastingly, participant Yasser perceived such support, whereby his teacher **prevented him from reading aloud** in front of his peers, as being a positive form. Once Yasser moved to the private school (fee-paying school), the educators there provided sufficient assistance, with Yasser providing an example:

'I got a great deal of support from my teachers. Sometimes I could provide written responses for the teacher, while others would not even test me and simply gave me full marks'.

Yasser elaborated on how he believed he was perceived favourably by certain educators when they permitted him to provide written responses rather than participate in the standard oral assessments. Data in this section further illustrate the nuanced and different ways in which PWS respond to school support, and the consequent importance of hearing their voices as individuals with differing needs (this point is discussed in Chapter 7).

# 5.4.1.3: Perceptions of Teachers' Feedback

Teachers' feedback was deemed to affect how participants perceive themselves and their stuttering. Five participants spoke of the impact of teachers' words on them (Table 5.11).

Table 5.11: Participants Perceptions of their Teachers' Feedback

<b>Participants</b>	Teachers	Positive	Negative feedback		
	feedback's	feedback			
	affected self-	Affirmative	Negative	Mistreatment	Discussed
	esteem	attitudes	comment		his
					stuttering
Fahad	✓				
Yasser		✓			
Sarah			✓		
Baraa				<b>√</b>	
Rakan					✓

Participant Fahad deemed his educators' feedback to have **affected his self-esteem**, with stories linked to this issue featuring prominently in Fahad's life story. Although Fahad did not relate long narratives in this regard, he clarified the effect that his educators' words and appraisals had on his self-esteem. Fahad related that when his teachers provided positive feedback his self-esteem would increase, and vice versa:

[A teacher said] 'why do you talk like that, are you scared?' My self-esteem become very low. Another teacher remarked positively: 'you can read very fast', and he called another teacher over to see how I could read very fast, so my self-esteem increased.'

Fahad plainly stated that his teachers' feedback and comments affected his self-esteem, thus indicating educators' potential role with regards to shaping students' self-esteem and self-image.

Participant Yasser deemed the majority of his educators to have had **affirmative attitudes**, while he appreciated their encouragement of him. An example is how one of his intermediate school teachers expressed their eagerness to support Yasser, and offered him affirmative feedback to promote his engagement in class discussions and activities when Yasser began evading this:

'I sat towards the back of the class in intermediate school [...] God bless the teacher who used to tell me to stand up, stating 'you are clever, why didn't you respond? You can have more time.' He was aware of my stutter.'

The positive feedback from teachers that Yasser received might have reflected positively on him, given that he considered his teachers to be accepting of him, while they also understood that he had abilities despite his stutter.

However, participants Sarah and Baraa said that they considered themselves to have received clearly **negative feedback** from their teachers during their school life. Sarah recalled a **negative comment** from one of her teachers which profoundly affected her:

'I was standing by the whiteboard trying to read but I was unable to complete the sentience. Then, the teacher asked for 'girls who can take turns, if we wait for her we will wait the entire day' [...] until now I still remember this in detail, my fear and silence.'

Teachers' comments and feedback, therefore, had a lifelong negative effect on Sarah, Yasser and Fahad.

Baraa pointed to his most difficult experience was his **mistreatment** by a high school teacher. Baraa explained that bullying by teachers was more difficult to cope with than that afflicted by students:

'The teacher made fun of me and if this behaviour had been from my peers, I might have accepted it, but from a teacher, it was very difficult.'

Thus, Baraa indicated his teachers' role in shaping his stuttering life experience. In general, Baraa's narrative was highly selective of his life story's details, therefore, choosing to relate this particular story signals the profound effect that his teacher's mistreatment had on his stuttering experience. While he may have received negative

feedback and reactions from his peers, he appears to have been less affected by them and did not discuss any negative reactions from them.

Similarly, Rakan continued to recall his sense of embarrassment when a teacher **discussed his stuttering** at school, although he acknowledged that people did this due to possessing insufficient awareness and experience of interacting with PWS:

'One of my teachers used to discuss my stuttering in front of the entire class; he used to say: 'I did not know that you stutter, how long have you been stuttering?' I responded to his questions and was sweating from embarrassment. Teachers' lack of knowledge results in them dealing with people who stutter in an uninformed way, which can have a damaging effect.'

Consequently, Rakan evidently felt awkward about discussing his stuttering in front of his teacher and peers. However, Rakan emphasised that during the era he was at school, accessing pertinent information was not straightforward unlike in the present period, meaning not all teachers were knowledgeable about stuttering.

Overall, the degree to which participants spoke about their educational experience is indicative of the role that their school years had in shaping their stuttering experiences. The participants' perceptions of their school experiences differed from positive to less positive experiences. The reactions of other people in schools, including teachers and peers, alongside particular pedagogical strategies, were the principal elements contributing to the undermining or facilitation of PWS' school experiences.

# 5.5: The Impact of Stuttering on Professional Life and Career Choices

Four participants mentioned how stuttering has affected their professional choices and performance. Participants Abu-Abdullah and Mohammed noted their difficulties with finding employment, while Kholod and Rakan, who are teachers, discussed the challenges they faced when they settled on their chosen career (Table 5.12).

Table 5.12: Stuttering Impact on Professional Life and Career Choices

Participants	Job choices and	Professional life and
	opportunities	performance
Abu-Abdullah	✓	
Mohammed	✓	
Kholod		✓
Rakan		✓

Regarding **job choices and opportunities**, Abu-Abdullah and Mohammed confronted problems with finding a job. Abu-Abdullah was unemployed for almost four years:

'Then I was unemployed from 2005 until the date 3-8-2008. This was the first day of my job.'

Meanwhile, Mohammed's stuttering prevented him from successfully participating in job interviews:

'My stuttering problem very much impacted my job searching as well, since it has let me down in various interviews, in which I become nervous and am unable to express what I wish to say'.

Also, he related a story concerning a job interview during which he could not express himself and he seemed to be affected by the interviewer's feedback and sympathies:

'I was unable to talk [...]. I could tell from how they looked at me that they pitied me. I was refused the job on the grounds that I am silent and cannot communicate properly [...] I could tell from how they looked at me that they pitied me.'

Mohammed clarified how he possessed requisite capabilities and knowledge, yet he was unable to convey this during job interviews, which subsequently resulted in him being declined several times. Even so, Abu-Abdullah did connect this problem to his stuttering. Such hindrances may be connected to his educational attainment, because he ceased his formal studies after high school; this might have contributed to Abu-Abdullah's job choices and options, rather than the requirement for high speaking skill for particular types of employment. Nevertheless, there is potentially an interactional and overlapping relationship between stuttering, educational attainment and job status, given that these may have interrelated effects. Stuttering potentially undermined Abu-Abdullah's educational performance (as he himself suggested), which subsequently restricted his job options.

**Professional life and performance:** Participants Kholod and Rakan are teachers. This career choice resulted in certain challenges ever since they began studying in the educational department and prepared themselves to become teachers. It also persisted later in their workplaces once they finally became teachers. Since pursuing her career choice of teaching and during her university days, Kholod was asked how she considered herself able to be a teacher with a stutter; a question she found irritating and intrusive:

'Of course, people are both curious and insensitive. Because to them, I'm different. They simply cannot grasp how someone like me is able to teach'.

Some individuals hold assumptions concerning the type of employment appropriate for PWS, considering certain jobs such as teaching to require perfect diction, therefore believing that they might be unsuitable for PWS (Boylea, 2017). The extent to which Kholod was affected by people referring to her stuttering was indicated by the very first thing that she wrote during the interview being:

'Aren't you surprised that I can be a teacher with this stutter?'

Therefore, Kholod expected a researcher to think similarly to others who surround her, which is to say, questioning the prospect of a person with a stutter becoming a teacher.

Through meticulous lesson preparation, Kholod is able to undertake direct teaching with only slight stuttering. Regardless, any extraneous material or necessary responses to students' questions may result in her stuttering emerging. Likewise, Kholod has discovered that her stutter hinders her from engaging in discussion with her colleagues in the staffroom. Kholod is frustrated at being knowledgeable about something, having the capacity to valuably contribute to a discussion, yet feeling that she must remain silent:

'I hate it when I am with my colleagues and they are discussing a topic I am familiar with and could contribute to, yet I cannot bring myself to speak'.

Kholod's stutter manifests primarily when she must incorporate unprepared material during a class or needs to participate in conversations and discussions with colleagues. These difficulties pose a barrier to Kholod improving her professional performance, because her stutter limits the efficacy of her interaction with her students and colleagues.

Similarly, Rakan's career choice of teacher was a significant aspect of his life story. Rakan explained that having completed high school, he opted to study at a teacher training college. He elaborated how this choice created difficulties for him from the outset; Rakan asked himself how he could pursue a teaching career while continuing to stutter. Even so, in the practical context of his final year field work at University, Rakan pointed to how he managed to transcend these challenges through self-preparation and self-education, which subsequently strengthened his self-esteem and provided him with the realisation that pursuing his ambition of becoming a teacher was the correct decision:

'How could I become a teacher when I stuttered? [...] I interned in a class as a teacher for the first time, and of course I read about what to do when teaching for the first time. I educated myself, so I managed to pass the first year and I was on the right path'

Rakan's positive university experiences, particularly during his field work, may have contributed to his enhanced stuttering experience. Consequently, he did not deem his stuttering as having been a barrier to becoming a teacher.

## 5.6: Participants' Difficulties with Social Interaction

Social interaction was viewed as a challenge for those participants who expressed difficulties with introducing their names and beginning conversations, as well as who faced listeners' negative reactions and bullying. Furthermore, participants discussed the role of social awareness in relation to the social difficulties they experienced. In addition to the impact of social interactions as teenagers, and the effect of stuttering on friendship.

## 5.6.1: Difficulties in Introducing Names and Starting Conversations

Participants conveyed their narratives about their communication difficulties confronted in social settings (Table 5.13); four participants faced challenges in introducing themselves and saying their names to others, alongside further difficulties initiating a conversation. In such circumstances, participants pointed out that their stuttering's severity was exacerbated. Yasser, Haifa, Alia and Rakan told stories about the difficulties they faced when saying their names, revealing that they sometimes avoided stating their real name and gave an alternative to avoid stuttering when saying them:

Table 5.13: Difficulties in Introducing Names and Starting Conversations

Participants	In educational aspects	At social settings
Yasser	✓	
Haifa	✓	
Alia		✓
Rakan		✓

Participant Yasser and Haifa found it problematic to introduce their name to teachers, which had a profoundly deleterious effect on the **educational aspects** of their life. During the second year of primary school, Yasser struggled to tell one of his teachers his name:

'When I was at primary school in year two, a teacher asked me to introduce myself.

I attempted to say my name but I was unable, before my teacher picked up my book

and read my name out. The teacher turned to me and told me 'your name is Yasser', to which I replied 'yes'.'

Beginning with introducing himself, Yasser was posed with numerous challenges during his school life. When the new school year began and all pupils would be asked to introduce themselves, Yasser would ask to be excused for the bathroom, or sought to skip lessons entirely in order to avoid doing so. Therefore, Yasser's school life was undermined because of his anxiety about and difficulties over introducing himself. He explained that instead of saying his own name, using names of other people is simpler for him. Indeed, Yasser's anxiety about his own name is ongoing; he sometimes finds it simpler to introduce himself as 'Yass':

'If giving my name had not been an issue at school, I would have had an improved experience. However, I have struggled with this until the present, with introducing myself being a great anxiety. It may be hard to believe, but I find it easier to introduce other people. Sometimes I simplify things for myself, rather than giving my name as Yasser I will say it is Yass, to avoid the challenge.'

Ultimately, Yasser's social and academic activities have been severely affected by his anxieties and challenges over giving his name. Without this problem, notes Yasser, his school life would have been far more tolerable.

Similarly, Haifa discussed events that she endured during school as a consequence of her struggles to say her name. This difficulty caused Haifa stressful situations with her teachers and peers. Indeed, the problem with saying her name typically presented in school, when her teachers asked for her name and placed her in embarrassing situations:

'Saying my name is a difficult thing [...] I could not say my name and heard a group of girls laughing, I felt bad and I felt that it is not funny.'

In certain instances, Haifa's friends would support her, telling her name to the teachers instead. Nevertheless, Haifa said that she expressed mixed feelings over receiving such support; certain times she felt relieved, whereas other times she would feel negatively about such intervention, especially if the teacher responded by asking Haifa why she did not say her own name:

'whenever the teacher asked me about my name, I would feel very nervous and stressed, so I felt very happy when my friends saved me from this difficult position,

although afterwards I would think why [I cannot say may name], and I would have negative feelings.'

Haifa's ambiguous feelings might have stemmed from her sense of the challenges she faced in being unable to state her name, although she still felt pleased when her friends supported her.

Participants Alia and Rakan faced complications with speaking their names during **social engagements,** for example while in cafes and other social contexts. Alia remarked that she stutters considerably when wanting to provide her name to a greater degree than she does when providing other people's names:

'In Starbucks when they ask me my name I do not give them my real name, because I know I will stutter when I say it, so I give them another name'

Alia explained how her stuttering is potentially linked to her state of mind, when she feels she is in a stressful situation or anticipates that her stutter might be exacerbated.

Participant Rakan said that he continues to confront difficulties while introducing names and beginning conversations with strangers:

'When I introduce myself to people I have difficulties, as well as at the start of conversations [...] I remember when I applied to study at the Air Academy, during the personal interview I was told by the general who interviewed me that: 'At the beginning you were stuttering, but then you talked normally'.

Accordingly, Rakan's stuttering and the stressful situations he finds himself in, for example introducing himself and starting conversations, seems to affect his social interactions. Rakan evidenced this through recalling a story of a time another person told him he was stuttering at the outset of their conversation. This story supported Rakan's narrative, leading us to the understanding that Rakan's perspective may have been influenced further by others' perceptions of him. Consequently, social interactions potentially played a significant role in exacerbating Rakan's challenges, while potentially reflecting his previous social experience. The role of social interactions on PWS' perceptions of their experience will be further discussed in Chapter 7.

## 5.6.2: Participants' Perceptions of Listeners' Reactions

Six participants—Alia, Baraa, Maha, Haifa, Kholod and Sarah—interpreted and described others' reactions to their stuttering (Table 5.14). They identified negative

reactions from others that included facial expressions, such as raising their eyebrows, gazing at them, and averting their gaze, as well as expressing sympathy towards them.

Table 5.14: Participants' Perceptions of Listeners' Reactions

Participants	F	acial expressions	Sympathy
Haifa	<b>✓</b>	•	
Alia	<b>✓</b>	•	
Baraa	<b>√</b>	′	
Maha	<b>√</b>	′	
Kholod			✓
Sarah			✓

**Facial reactions** in general, in addition to gazing and **averting one's gaze** in particular, were mentioned by participants Alia, Maha, Baraa, and Haifa as being negative reactions of others in response to their stuttering. Alia discussed certain facial reactions of people when she stutters:

'[Some people] gaze at me [...] sometimes when I talk to people and stutter, they move their eyebrows and eyes and get nearer with their ears, which makes it worse'.

Similarly, while participant Maha made little comment regarding others' reactions to her stuttering, she emphasised that when listeners react with facial expressions to her stuttering, she does not like this:

'I hate when people stare at me like I am abnormal, they cross their eyebrows'.

In this regard, Alia and Maha's narrative expressed the negative feelings they feel when other people show facial reaction, which make them feel as if they were 'abnormal'.

However, Haifa identified that her most disliked listener reaction is when somebody averts their gaze from her when she stutters. She considered such responses as suggestive of disrespecting her, compounding her stress and exacerbating her stutter:

'I did a presentation [...] what depressed me the most is that my friends did not look at me, as if they were ignoring me [...] Even at home I hate it if my family do not look at me when I talk. I know I make some facial expressions when I stutter, but I do not think this should make them unable to look at me.'

Haifa emphasised that she does not want other people to avoid directly looking at her when she stutters. Consequently, the type of support that certain individuals offer in an attempt to reduce Haifa's stress—for example avoiding eye contact with her—actually increased her stress and anger.

Regarding **sympathy**, this is something participants reacted negatively to. Kholod and Sarah received the sympathy of others, and explained that this is a reaction that they not only disliked – they hated it. They noted that when they stuttered in front of others, certain people expressed sympathy as though they should be pitied. As Kholod related:

'When people meet me [...] once they realise that I stutter, they regard me as someone to be pitied. They find it embarrassing or too much trouble to talk to me'.

#### Meanwhile, Sarah said:

'I told him [a speech therapist] that the thing that most upset me is that people perceive me with sympathy. He [the speech therapist] suggested that sympathy is not a bad thing and that humans are emotional'.

However, Kholod and Sarah said that they felt uncomfortable when receiving sympathy from others, believing it to be unnecessary. This is because they deemed themselves to be strong people, thus not be viewed with sympathy. Therefore, despite the speech therapist suggesting to Sarah that people's emotional responses are to be expected, such reactions may detrimentally affect PWS' social experience (Constantino et al., 2017).

## **5.6.3: Bullying**

Four participants talked specifically about being bullied, primarily in schools, although they also endured it at home and in social contexts (Table 5.15). Abu-Abdullah and Mohammed discussed the long-lasting effect of their **childhood bullying**, whereas Alia and Tara noted they developed **resilience** to the bullying they experienced.

Table 5.15: Perceived Experience of Bullying

Participants	Childhood bullying	Resilience
Abu-Abdullah	✓	
Mohammed	✓	
Alia		✓
Tara		✓

Abu-Abdullah's real-life story included numerous examples of social ostracism and teasing from others. However, Abu-Abdullah elected to relate one particular story concerning a negative reaction of a boy during primary school, which significantly affected his feelings:

'I experienced too many stories and events [...] one time, one boy called me 'disabled'. I could not stand this word and I slapped him in his face, and I told him 'do you see how the disabled slapped you or not?' [...] I am very sensitive person [...] I said I don't care, but after that I don't know what happen to me.'

Thus, irrespective of Abu-Abdullah having experienced numerous negative social interactions, he opted to relate this specific story due to believing it had a profound personal effect on him. Furthermore, Abu-Abdullah stipulated how he tried to disregard other people's remarks and perspectives, although he could not manage to do so. Therefore, Abu-Abdullah's narrative effectively indicates the significance of words or a word's value in shaping Abu-Abdullah's reconstruction of his overall life story, as well as his social interactions in particular.

Childhood and school-based bullying, alongside insufficient support, had a severely detrimental effect on participant Mohammed's perception of his entire life story. Indeed, Mohammed has continued to suffer from his negative childhood experiences of bullying. When he recalled what had happened to him, Mohammed remarked how he continues to feel particularly bad, as if his bullying experiences are recurring:

"The hardest period of my life was during my primary and secondary school years [...] I was constantly being made fun of with no form of support. I would cry a lot when I came home, and I was unable to confide in anybody about my problems."

Essentially, Mohammed has not managed to transcend his adverse childhood experiences, due to being a victim at that time with an inability to defend himself or counter his bullies' behaviour. This made him wish that he could have defended himself, or had someone to support him during the times he was being bullied. During the interview, Mohammed seemed especially upset while discussing being bullied, and for this reason I did not probe further into this negative experience for him.

Contrastingly, participant Alia explained how she developed greater **resilience** having experienced substantial bullying at school, at home and in social settings. Intermediate school was the most common period during which Alia experienced bullying, teasing by other students and negative comments from teachers if she stuttered while reading or saying her name:

'Bullying was mostly during intermediate school [...] At home, my sister always bullied me, everywhere there was bullying. But after many hard experiences and a lot of crying, I developed resilience.'

Alia experienced bullying primarily at intermediate school, which was potentially a consequence of her peers' age, because the majority were teenagers and possibly insufficiently mature to regulate their behaviour. Moreover, Alia's teachers' comments potentially indicate their inadequate grasp of the need to protect students' feelings. Nevertheless, Alia's resilience may have stemmed from this negative experience, having enhanced her capacity to accept other's maltreatment without being significantly affected.

Likewise, Tara conveyed how, because negative social engagements have largely pervaded her life—for example bullying and teasing, or comments about her facial expressions linked to stuttering—she has established resilience. Tara said that she has realised that not all individuals she engages with will be sufficiently educated and possess awareness of her condition, so she must accept all manner of people in society, including those who mistreat her:

'I do not feel sad as a result of other's bullying, because I have become resistant [...] not all people in society will be educated [...] and I will need to accept all different people in society'.

Tara clarified that typically she does not relate much information regarding her negative social interactions. Therefore, they consume less space in her thoughts, meaning she recounted no in-depth recollections of social maltreatment she has potentially experienced as part of her life story. Instead, Tara simply mentioned her acceptance that she will engage with people during her life who lack awareness or education. This potentially indicates that Tara does not deem such detrimental experiences to be a significant aspect of her life story.

In summary, certain participants indicated that their memories of being bullied during childhood affected their lives, with it being difficult to eliminate its effect. Meanwhile, alternative participants expressed a need to mitigate bullying's effect on them.

# **5.6.4:** The Role of Societal Awareness on Stuttering Experience

Three participants' life stories referred to public awareness; Yasser and Ali described their societies as **lacking awareness**, whereas Omer believed positive change and **improvement in societal awareness** was presently occurring (Table 5.16).

Table 5.16: The Role of Societal Awareness on Stuttering Experiences

Participants	Lack of awareness	Improved social awareness
Yasser	✓	
Ali	✓	
Omar		✓

A dearth of societal understanding was observed by Yasser, given that some people perceived him as mentally ill, or mock those who stutter:

'The illness of stuttering is not something that is sufficiently understood in society. People might believe someone is crazy if they are stuttering. For instance, I hailed a taxi once and was attempting to provide directions to the driver. However, I was stuttering and the driver was fearful, so drove off. Now I use Uber or 'Kareem' to book taxis, because I do not need to speak the directions, I can enter the location in the app.'

Notably, Yasser referred to his stuttering as an 'illness', while suggesting that stuttering is insufficiently understood among wider society. I inquired further into Yasser's characterisation of stuttering as an 'illness'; he clarified his understanding of stuttering as a chronic ailment, comparable to depressive episodes, which hinders a stutterer from communicating effectively: 'It is an illness because I am unable to interact with others effectively, it is similar to the psychological issue of depression or other chronic illnesses'. In this regard, his personal perspective and opinions of individuals in society concerning stuttering are congruous; both perceive stuttering unfavourably.

Ali pointed to society's marked role in his stuttering experience. He appeared to have thought considerably about other people's perceptions of PWS, which possibly negatively impacted him, because he asked himself whether his experience would differ if he resided a society with enlightened attitudes and awareness regarding stuttering and PWS:

'I often find myself feeling marginalised and alienated and longing to be part of a more sensitive and knowledgeable society, where people who stutter are accepted and not treated like deficient or damaged individuals.'

#### He continued:

'As a stutterer [...] I am sure that a more supportive and aware society would have made my condition far easier to bear, and to resolve.'

Thus, Ali evaluated his situation by comparing his real-life experience with the life he envisages would have been possible within a more supportive society. Evidently, a society with greater acceptance of people's differences would have improved Ali's life experience through reducing the difficulties stemming from social obstacles. However, Ali acknowledged that insufficient awareness is not society's fault, rather people must be educated to strengthen public awareness.

Contrastingly, Omer observed that **a positive shift in society's awareness** and understanding of stuttering has emerged recently. He remarked on his particular pride in seeing people's stuttering awareness develop. Omer indicated that nowadays, he resides in a more supportive society where his stuttering is not responded to negatively, whereas previously there was a dearth in awareness and more negative reaction to PWS:

'I feel the difference. Four years ago people did not know how to deal with a person who stutters. They used to stare at them or interrupt their speech, although now I perceive that people in society have sufficient knowledge. They are more relaxed when listening to someone's stuttering speech, waiting for them until they finish their speech [...] I have broken the barrier of fear.'

Omer emphasised his society's positive changes and developing awareness, with such changes potentially formulating a social environment within which Omer has been able to break the barrier of fear and practice socialising with others. Notably, this is potentially a prominent point connected to contemporary changes that are occurring broadly within Saudi Arabian society.

# 5.6.5: The Impact of Social Interactions with Teenagers

Some participants emphasised the role that growing older had in increasing their sensitivity and understanding of stuttering's detrimental consequences. Regardless of Ali and Rakan having stuttered since early childhood, they did not recognise it as a difficult issue until they were **teenagers**. These participants conveyed that the more they grew up during secondary and high school, the more their sensitivity increased to others' reactions and the greater their awareness of their stuttering's negative effect on their lives (Table 5.17).

Table 5.17: The Reasons for Increasing the Sensitivity of PWS During their Teenager's Years

Participants	Became more	Become more	Become	more
	aware of the	sensitive to	aware of	their
	negative effect of	negative reactions	differences	and
	stuttering	and feedback from	weaknesses:	
		other		
Ali	✓			
Rakan		✓	✓	

Ali related how the older he became, the more **awareness** of the problem he developed, with a growing **negative effect of his stuttering**:

'university had a more significant impact on me because, by this time, I was fully aware of the problem, and for the most part when we experience problems and are aware of them, this has a strong effect on us.'

Life experience may have played a role in exacerbating the effect on Ali of his stutter; previous experience may influence his evaluation of his stuttering as an issue affecting his life. Consequently, Ali stated that his stuttering experience was markedly worse during adulthood compared with his childhood.

Additionally, participant Rakan indicated that his most challenging time during his life was as he became a teenager and entered secondary and high school. Subsequently, he developed a stutter of greater intensity. Rakan explained that by this age, people expressed greater sensitivity, although they were also old enough to understand each **other's reactions**, their differences and weaknesses:

'Of course, as I became older, the severity of this problem increased. I think the adolescence stage may have contributed to this, or it may be that at this age one becomes more sensitive to other's reactions, and to my problem.'

Therefore, this period of adolescence seemed to play a significant role in shaping Rakan's life experience with stuttering, as he began developing sensitivity to other's feedback and opinions. Meanwhile, some participants noted that they were sufficiently mature by this point to evaluate other's reactions to them, which contributed to their subsequent development of negative thoughts regarding their stutter.

## 5.6.6: The Effect of Stuttering on Friendship

Stuttering's effect on friendships with school peers was discussed by a number of participants, with particular mention of the loss of friendship as a negative result of stuttering, alongside the role of peers' support in stuttering experience (Table 5.18).

Table 5.18: Stuttering and Friendship

Participants	Loss of friendship		Peers' support	
	One Friend	No Friends	School friends	PWS' Online
				interaction
Yasser	✓			
Maha		✓		
Omar			✓	
Tara			✓	
Ali				✓

**Loss of friendship:** Stuttering was deemed by certain participants as having resulted in them having fewer social relationships with their peers. Following high school, Yasser's relationships with his friends and peers degenerated. Yasser received negative responses and appraisal from individuals of a similar age, while also having fewer friends:

'I had regular friendships with people previously, although this has changed. Actually, I have just one friend now.'

Regarding his associates and deleterious social relationships with others, Yasser explained situations wherein his stuttering would be emphasised by an individual if he sought to offer a counter perspective:

'One instance I found is that if I offer a correct perspective that differs from my associate's own perspective, they would divert attention from their incorrect opinion by concentrating on my stuttering and making an issue out of it.'

Additionally, Yasser was seemingly discontent with his interaction with associates and other students, because they would draw attention to his stutter rather than engaging with his opinions. Accordingly, it may be understood from Yasser's narrative of his social interactions with peers that the loss of friendship he experienced could have been a consequence both of his stutter and others' responses

Similarly, participant Maha remarked that she previously had regular friendships at school, although these circumstances worsened once she went to university. Here, she had no friends at all:

'In school I had some friends, yet at university I did not have any friends. I could not get close to any one and no one could get close to me. Five years without any friends.'

With hardly had any friends at university, this appeared to be a very challenging situation for Maha. Maha explained that she was unable to make friends at university. It may be appropriate here to observe that sometimes, the education type and environment at university may discourage students' socialisation with others, with students instead adopting a more individualistic learning approach to achieving their academic tasks, without engaging in efforts to develop their social skills (Laguado, 2014).

**Peers' Support:** Not all the participants had negative experiences. Three participants discussed the beneficial role of their friends and peers in improving their stuttering experience. Participants Omer and Tara referred to their peers' positive role in diminishing their stress and social difficulties. Furthermore, participant Ali illuminated how he befriended peers who were present on social media and shared an interest in stuttering, rather than being from school or workplaces. Participant Omer's friends filled a significant supportive role in enhancing his self-confidence:

'Friends have had a significant role in encouraging me and providing me with confidence. They would say, 'you can, go and talk' [...] I am fortunate that I have such people in my life.'

Accordingly, Omer's close friends appeared to have provided him with the space and surroundings wherein he felt accepted and encouraged, which, as Omer indicated, enhanced his stuttering experience.

Moreover, Tara recalled that peers' support during secondary and high school meant that she did not confront any challenges, due to her peers being those same students who were with her since fifth grade:

'During secondary and high school, I had the same peers who were present at the elementary stage, I mean from fifth grade at elementary school, meaning I did not experience difficulties'.

Thus, Tara's schooling experience was characterised by stability, given that she was not compelled to meet unfamiliar peers and manage relationships with them while transitioning from elementary to secondary and high school. Evidently, Tara's robust friendships and knowing her classmates over a number of years potentially reduced her stress levels, while providing her with a level of social support that subsequently enhanced her school experience.

Furthermore, PWS' support for each other via **online social media** was emphasised by participant Ali. Ali explained that his engagement in a PWS group was his most affirmative life experience. However, Ali suggested that the positive outcome of these groups did not last for long after the groups finished, because his severe stutter returned:

'Things changed in 2014, I set up a WhatsApp support group for people who stutter. The group had over 100 members, who came from many different places, and our only common ground was the fact we stuttered. We wanted to support each other, and in the process every member shared their story and stuttering experience, so as to help, encourage and provide psychological support for the others.'

Ali's experience demonstrates the human need to belong to a group of people who are similar to them and share similar experiences. Accordingly, it indicates that PWS may derive substantial benefit from engagement with each other, as they can share their experiences and challenges with individuals who have endured comparable things. Additionally, this story illuminates the advantages of adopting technology to support PWS with finding other people with similar experiences, knowing that there is less likelihood of meeting a large group of PWS in a regular place. Thus, although certain participants experienced loss of a friendship because of their stutter, online gatherings of PWS may provide a degree of support that can enhance their stuttering experience.

#### 5.7: Avoidance

Thirteen participants observed that their challenging previous experiences and deleterious social interactions produced their negative emotions, such as stress and shame, resulting

in their adoption of avoidance behaviours as a means of evading such negative feelings. This section considers the avoidance of negative reactions, avoidance of being judged by family members, as well as avoidance of stressful situations. As well as participants' avoidance methods implemented to avert stressful situations, the perception of avoidance as being a problem in different contexts was considered.

## **5.7.1:** Avoidance of Negative Reactions

Three participants conveyed how they avoided conversations to evade experiencing others' adverse reactions. Some peers and teachers' negative reactions were seen to involve negative comments, teasing, mockery and laughter when the participant stuttered (Table 5.19).

Table 5.19: Avoidance of Negative Reactions from Peers and Teachers

Participants	Negative reaction from	Negative reaction from
	classmates	teachers
Ali	✓	
Omar	✓	✓
AL-Anood	✓	✓

Ali recalled how **negative reactions from his peers** in schools and at university have negatively affected his educational experience. Ali typically avoided class activities; at university, he evaded participating in educational activities such as presentations:

'I invariably attempted to speak as little as possible and tried to not get involved in classroom activities, because my classmates mocked me and teased me when I spoke.'

On this basis, Ali's negative experience of others' reactions to his stutter can profoundly affect his educational and social life. When he experienced negative social interaction and subsequently sought to avoid social interactions in classroom, he might develop particular social character, such as avoid being involved in conversations.

Because of teasing afflicted on Omer by certain **students and teachers** at school, Omer engaged in avoidance behaviours:

'I avoid standing in front of the class and present a speech, because students would laugh at me or mock me. Unfortunately, I was easily negatively affected by their reactions [...] Some teachers also used to engage in indirect negative commenting.'

Omer explained that he endured a negative school experience because of his fears and unhealthy social relationships with his peers and teachers, leading him to evade participation in school activities.

Similarly, because of Al-Anood's embarrassment due to others' reactions at school and in social contexts, she adopted avoidance behaviours. Irrespective of the fact that she perceived herself to be a good student while at school, she limited her class participation to prevent herself from being on the receiving end of teasing and staring among her peers and teachers, which made her feel ashamed:

'Although I was one of the top students in my class, I did not participate in class activities. [...] I preferred to remain silent to avoid students and teachers' staring. I felt embarrassed if other students laughed at me when I spoke. I felt fear and stress, and my voice changed when I spoke in front of others, so most of the time I was silent'

Accordingly, Al-Anood's adopted avoidance behaviours is connected to her desire to obscure her stuttering, therefore averting embarrassing and stressful situations stemming from her speech challenges during conversations. Thus, some participants indicated that they would prefer not to participate in social activities, if they would be a subject of others' negative reactions, such as gazing, teasing and laughed at their stutter.

## 5.7.2: Avoidance to Prevent Being Judged by Families

Two participants discussed how their avoidance behaviour stemmed from a wish to avoid their **families**' negative judgements and reactions, which involve looking for improvement, sympathy and criticisms (Table 5.20)

Table 5.20: Families' Negative Judgment and Reactions Led to Avoidance Behaviours

Participants	Family looking for	Sympathy and criticisms
	improvement	
Sarah	✓	
Tara		✓

Sarah said that she reduced the extent of her communication with family members and cousins, due to feeling that they judge her speech and appraise whether any improvement in her stutter has occurred:

'I talk a little in front of my family, which may be because I feel that they are judging my speech and waiting for some improvement, so I always attempt to hide my stuttering'.

In this regard, Sarah has sought to hide her stutter for different reasons. Sometimes it was to avoid alerting people to the fact that she stuttered, while at other times she has hidden her stutter from people who seek some improvement in her condition.

Maha has attempted to hide her stutter from her family for much of her life story. Maha explained how she felt uncomfortable stuttering around her family:

'I don't feel comfortable stuttering in front of my family. It shouldn't be the case, you know, people shouldn't worry about stutter around their families. But for me, I prefer not to stutter in front of them'

At present, Maha has avoided stuttering around her family, which is potentially related to numerous reasons. For example, Maha pointed to her mother's expression of **sympathy** for her when she stuttered in front of her, meaning Maha has avoided engaging in conversations with her mother.

'When I stuttered in front of her [her mother] she would not say anything, although I felt she looked at me with sympathy and she would exhale, like 'ah' [...] She did not treat me very well, but it was better than my dad.'

Additionally, she narrated her father and brother's **criticisms** of her stutter. Although her mother did not appear to play a positive role in Maha's life, Maha still deemed her relationship to be better than that which she had with her father. Maha's perspective on her parental relationships potentially highlights her need to have a loving parent; while her mother was not particularly supportive, Maha still appreciated that she was at least better than her father. Consequently, the sentiments and responses of Maha and Sarah's families might have shaped their preference for avoiding stuttering in front of them.

## 5.7.3: Avoid Stressful Situations, and Methods of Avoidance

Six participants explained their avoidance of participation in school activities and social interactions, thus safeguarding themselves from stressful situations (Table 5.21).

Table 5.21: Avoid Stressful Situations in School and Social Sittings

Participants	Avoid school's	Avoid social	Methods of avoidance
	activities	interactions	
Rakan	✓		No data were provided
Maha	✓		
Baraa		✓	
Sarah		✓	-Word replacement
			-End the conversation
Fahad	✓	✓	-Provide short answers
Alia	✓	✓	-Absent from oral exams
			-Allow other students to present
			before her, hoping that they run out of
			time before her turn.
Yasser	✓		-During team work, he would evade
			contributing to verbal presentations

Stressful feelings stemming from stuttering within social contexts meant that since childhood, Rakan and Maha resorted to evading **school's activities**:

#### Rakan said:

'I avoided participation in the morning school activity [a school activity happening every morning before classes, during which students have to talk in front of the whole school], even memorising the Quran [the Islamic holy book], I was trying to avoid everything. I felt something like fear.'

Rakan's previous stressful experiences and anxieties around stuttering in social contexts possibly led him to avoid or limit his social engagement and interactions. Ultimately, Rakan has sought to avoid repeating his participation in these negative situations.

Similarly, because of fears and embarrassment that Maha faced during school, she adopted avoidance behaviour. Once she started acknowledging and focusing on her stutter during fifth grade of primary school, her anxiety around class participation emerged because she wanted to avoid feeling ashamed:

'I was standing before my peers holding a paper. My hand was shaking and I cried [...] Since then I avoided participating in school activities. Sometimes I participated just to receive a good grade, rather than through any willingness to participate.'

Maha recalled how, from the fifth and sixth grade of primary school until her attendance at university, she avoided participation in academic activities. She added that if such participation was necessary to maintain effective performance, then she would contribute, albeit keeping this to a minimum.

Participant Baraa related how his fear of stuttering in front of others, alongside his desire to obscure his stuttering, has resulted in him **avoiding social interactions**:

'I avoid and I fear engaging with people. For example, when I want to order food from restaurants, or I am anywhere and have to talk to anyone to ask about something, I will stutter'.

Baraa provided an example of a stressful situation he confronted as a stutterer, highlighting three elements, namely avoidance, fear and stutter. Thus, Baraa avoids social engagement as a consequence of being fearful of stuttering around others, and to avert stressful circumstances that trigger his stuttering. This illustrates a tense and heightened relationship for Barra between his anxieties about his stutter and his avoidance behaviours.

**Avoidance Methods:** During school, Sarah, Fahad and Alia also adopted various methods to avoid conversing or entering into discussions. Sarah stated that there are particular situations where she attempted to hide their stuttering out of the shame she would feel. She would adopt various ways of hiding her stutter, for example **replacing the words** that make her stutter with other words that she finds easier to pronounce, or just stop talking and **end the conversation**:

'For example, if I was in a restaurant with friends who I wasn't very familiar with, I would change my order to avoid stuttering. Or when I want to participate in a conversation I simply stop talking, to avoid placing myself in an uncomfortable situation.'

Sarah hid her stuttering from people who were unaware of it and who might judge her if they knew about it, which would make her feel uncomfortable.

Similarly, due to Fahad's negative experiences at school, he started talking less often both there and in other social contexts, seeking to hide his stutter. Consequently, Fahad noted how, while he is engaged in conversation, he only offers very brief responses:

'If someone talked to me I would just give very **short answers**, similar to how I would in a personal interview. I want to hide my stuttering.'

Through seeking to obscure his stutter, Fahad's social life might have been undermined, because he intentionally avoided social interactions.

Alia **absented** herself during oral examinations to evade such stressful situations, or hoped that the lesson time would finish before it came to her turn to present orally:

'In primary and intermediate school, if the following day I had to read or make an oral examination I would not attend school. But in high school I could not do this because it would affect my overall score.'

## Alia explained further:

'I allowed all my friends to make their presentations before me, hoping that we would **run out of time** before it was my turn. When it was my turn and I was about to start, the time finished as I wanted, but I went away and cried, because I felt low self-esteem.'

Furthermore, Alia clarified how the majority of events she related as part of her life story were connected to school because she was compelled to talk there.

Yasser's avoidance behaviours also caused him to **evade contributing to verbal presentations**. Instead, Yasser would undertake research, create slides and provide written material in contribution to group work. That in turn led him to being negatively judged by his peers. Regardless, Yasser suggested there was insufficient appreciation of his efforts:

'For one class we had to prepare a presentation, which meant I certainly wanted to evade providing the verbal presentation. Instead, I completed almost all the preparation work for our team, arranging ideas and preparing the PowerPoint. All my colleagues had to do was present in front of the class, yet somebody commented 'Yasser is useless', which left me stunned. I was unable to breathe and indeed felt useless.'

Yasser's personal exertion and work was unrecognised due to his avoidance behaviour, and this subsequently undermined his feelings of self-worth and his self-concept. Thus, avoidance behaviours at university were considered as a significant issue for Yasser.

## 5.7.4: Perceived Avoidance as a Problem in Different Context

Avoidance behaviour was perceived variously by the participants, who tended to deem it a problem if it negatively affected elements of their life such as education, professional performance and social aspects. Two examples from Haifa and Mohammed respectively explain how avoidance behaviours affected their stuttering experience. Haifa adopted avoidance behaviours in social contexts, although she did not avoid participating in

school. Haifa avoided beginning conversations in social settings, for instance in family gatherings or during interactions with cashiers:

'If we were at a family gathering and everyone started greeting each other, they would initiate it not me'.

If she needed to purchase items from the pharmacy, she typed what she required on her phone and handed it to the cashier:

'For example, when I go to the pharmacy, I type everything on my phone and I just hand my phone to him, and he would give me the things'.

Nevertheless, when comparing Haifa's academic and social life, Haifa has evidently forced herself to participate in school activities to a greater extent than in other social contexts:

'I wanted to be a good student, so I raised my hand when I knew the answer even if I was unsure whether I would be able to say it or not'.

Throughout Haifa's life story, she seemed to give greater thought and attention to her education. Indeed, Haifa had not avoided school activity participation, given that she has sought to ensure her robust academic progress and attainment of the necessary grades to attend medical college. Even so, Haifa did not express an equivalent desire to enhance her social life, having adopted avoidance behaviour in certain social situations.

Participant Mohammed also considered avoidance in school, workplace and social contexts as an issue, although he did not perceive his avoidance behaviours in the domestic environment a problem. Because of negative social interactions, Mohammed had stopped socialising with others since childhood. Mohammed adopted avoidance behaviours to protect himself from stressful circumstances and negative reactions. Moreover, Mohammed attempts to hide his stuttering to prevent others' judgements:

'It is fear that prevents me from talking in front of others, that my stutter will be apparent and I will be judged'.

## He also stated:

'I would actively seek to avoid speaking in front of others, instead preferring to listen.'

Such avoidance behaviour was initiated during childhood and has endured into the present. Mohammed avoided participating in school activities because of the bullying and teasing he was subjected to. During adulthood, Mohammed has continued his avoidance behaviours, which has translated into ineffective participation in and contribution to workplace meetings, thus undermining Mohammed's professional development. Interestingly, Mohammed explained that he avoids speech with his wife and children but he does not deem this to be a significant issue:

'I am married and have three children. My life is happy, and my family are unaware of my stuttering problems. This is because I do not speak much at home, I am silent for a lot of the time, so my stutter is not very apparent.'

Thus, although avoidance behaviour characterises Mohammed's entire life story, his interpretation of this avoidance behaviours has affected his understanding of its implications. Accordingly, Mohammed has interpreted such behaviours as a problem when it affected his educational and professional performance, yet not in the domestic setting, because hiding his stutter from his wife and children has not produced a direct detrimental effect. However, it is particularly lamentable that Mohammed adopted avoidance behaviours at home to hide his stutter from his wife and children, as this may have detrimentally affected his home life and relationship with his family, as well as his role as a husband and father. Additionally, this might indicate the large extent to which Mohammed adopted avoidance behaviours, even at home where he should have felt relaxed and not needing to hide his stutter.

# 5.8: The Impact of Stuttering on Sense of Self

Five participants discussed their stutter's effect on their self-concept and self-confidence; the majority expressed these as being interlinked concepts (Table 5.22)

Table 5.22: The Impact of Stuttering on Participants' Self-Concept

Participants	Elements led to lo	Self-concept as	
	Comparing Resulted from		affected by age and
	themselves to other's feedback and s		social expectation
	others	perspectives	
Yasser	✓		
Alia	✓		
Ali	✓		
Mohammed		✓	✓
Baraa			✓

## **5.8.1:** Elements that Led to a Low Self-Concept

Stuttering was identified as having deleteriously affected participants' self-concept, which was also detrimentally affected by negative social interactions and reactions in school and social settings due to their stuttering. Participants Yasser, Alia and Ali indicated that their sense of low self-concept stemmed from **comparing themselves to others**, whereas Mohammed's self-concept was formulated from **other's feedback**.

Yasser expressed his limited self-acceptance of being a stutterer stemming from him comparing his speech with most other people who do not stutter. Consequently, his self-perception was negatively affected by his stuttering:

'My self-acceptance continues to be very limited and I perhaps want to talk in the same way others do [...] Because I am unable to express myself, I have low self-confidence, with the opinions of others as well as my own feelings producing this self-perception.'

Therefore, Yasser's self-acceptance and aim of concealing his stuttering might be correlated. If somebody has self-acceptance of their stuttering, concealing it from others is no longer the aim, thus their overall stuttering experience may be improved.

Alia conveyed how her low self-concept resulted from her stuttering. She deems herself as below other people and hates her stutter, given that it has affected her social and academic life:

'I feel that I am less than other people. I hated the stutter because I think it prevented me from participating, it prevented me from achieving the overall score that I wanted, it stopped me from progressing in my life.'

Arguably, the detrimental consequences of stuttering, for example avoiding stressful situations, alongside negative social interactions both in and outside school, might have exacerbated Alia's difficulties and hindered her from fulfilling her aims. Subsequently, this may have undermined her self-concept.

Comparably, participant Ali's life story had the central theme of 'the question' that he has asked himself, namely 'why am I different?', which might have potentially been constructed via his social interactions. During his first year of schooling, he began asking himself why he was stuttering, why he could not speak like his peers and why other people were mocking him. Such questions possibly emerged as a consequence of Ali comparing

himself to the larger group, in addition to others' reactions and feedback which made Ali realise that he stutters:

'Beginning in the first year of elementary school, when I first started to wonder and ask myself why I could not speak like everyone else'.

Therefore, negative social interactions where acceptance of individuals' differences is not expressed may determine how a PWS perceives their stuttering and experience of stuttering. Ali developed consciousness of his stuttering after starting school, because his social interactions with non-stuttering peers involved their mockery of him which emphasised Ali's stuttering. Subsequently, Ali compared himself with them and identified himself as distinct from them due to these interactions. In turn, this has resulted in Ali developing a self-concept of himself as a stutterer from an early age.

Participant Mohammed clearly expressed how his self-concept and self-confidence were shaped as a reflection of **other's feedback and perspectives** of him. Mohammed explained how his self-concept as a stutterer was initially developed as a reflection of his classmates' negative reactions and feedback. Consequently, Mohammed may have formulated his self-concept and self-confidence based on being an individual with a speech problem, stemming from other people's feedback and reactions:

'I was seven years old when I first noticed that I stuttered. I became aware that I could not correctly pronounce the letter 's', but rather I would say 'sh'. I have noticed that from my peers, one day I entered the classroom and I said 'Alsalam ealykum' [an Arabic greeting]. My classmates responded with 'wa ealykum alshalam', which was essentially a way for them to make fun of me. It was then that I noticed that I was not saying the letter correctly.'

Mohammed constructed his self-concept of his abilities as an individual with a speech problem based on his social interactions throughout childhood and into the present. He began understanding his speech problem aged 7, when Mohammed started school and began social interactions with people outside his family. Deleterious social interactions with his peers, during which Mohammed was mocked due to his speech errors, made him realise that he had a speech problem. Furthermore, the comments and reactions of others contributed markedly to the development of Mohammed's self-concept, ultimately leading to his limited self-confidence.

Moreover, Mohammed's construal of others' perspectives shaped his self-concept, as he considered these to be characterised by negative feedback and comments (overlapped relationship):

'I often think about it. Other people would often use the word 'abkam' [deaf-mute] to describe me, meaning that I was a person who could not talk, and I ultimately started to believe this myself. I then lacked any self-confidence regarding my speech. Until now, I have never considered myself to be a strong or talented person.'

In this regard, the manner in which Mohammed perceived others' opinions contributed to his understanding of his life story. Mohammed indicated that his life experience may have been determined by other people, in terms of receiving and managing their feedback and reactions. This possibly shows how social interactions have had a significant role in shaping Mohammed's self-perception of his stuttering life experience.

## 5.8.2: Self-Concept as Affected by Age and Social Expectations

Social expectation may affect how people of a certain age perceive themselves. One example would be the possible social expectation that adults need to manage to establish their ability to live independently. Accordingly, the self-concept of adults who stutter may affect their fulfilment of social expectations. One instance related by participant Baraa concerned their negative emotions around still continuing to stutter aged 23, although he stated that the most significant moment in his life was having graduated from university. While participant Mohammed noted that as a person aged 40, he does not require any support:

The social and educational context might have affected participant Baraa's self-concept. Because of the difficulties Baraa experienced when attempting to socially interact with others, he felt ashamed of his continued stuttering into adulthood and because of how others looked at him:

'I felt shy and ashamed of myself because I have reached this age and I still stutter. I felt everyone's gaze resting on me'.

Therefore, negative social interactions and others' reactions possibly affected Baraa's self-perception. Additionally, Baraa indicated that the foremost event in his life was graduating from high school and university, which suggests that his educational experiences were pivotal in shaping Baraa's life generally. Ultimately, educational attainment might have significantly shaped Baraa's life experience and his self-concept:

'The moment of my graduation from university; I can state that this was the happiest moment of my life, because I had achieved one of my goals [...] I want other people to describe me as a person who supports others.'

Baraa's hope that other people perceive him as an individual who supports others might stem from his specialisation in psychology. Consequently, he has constructed his selfconcept based on his educational background.

Mohammed's final sentence prior to the interview's conclusion made a significant point that clearly presented how his self-concept was possibly affected by social norms and social power. When Mohammed was asked whether he wanted anything from his family or his wife, he remarked that at his age he does not require anything from them. Such a belief is likely to have been constructed in accordance with Saudi Arabian norms regarding social roles and power, because by age 40, men are expected to be sufficiently strong and independent to care for their family without any support:

'At my age I don't need anything from them [his family]'.

Consequently, Mohammed possibly formulated this belief underpinned by his understanding of Saudi Arabian society's social roles, norms and power, wherein men are those possessing power; Mohammed is an adult Saudi male who should not need family support. Rather, Mohammed should be providing his family with financial support, as a means of fulfilling his social expectations and societal role. In this regard, PWS's social interaction may play a significant role in shaping their self-perception and stuttering (Daniels et al., 2006). Furthermore, social expectations' effect may also produce self-criticism (Singer et al., 2013).

## **5.9: Treatment Limitations**

Not all participants discussed their experiences with speech therapists. However, two participants pointed to the barriers that have prevented them from engaging in speech therapy sessions. These obstacles concerned financial and social difficulties.

Tara opted not to visit a speech therapist and pathologist until the present time, based on two reasons. First, when Tara was younger no female specialist was accessible, while it would have been problematic for her to participate in sessions with a male therapist. Consequently, Tara received no treatment at an early stage. Secondly, more recently inflated prices have hindered Tara from pursuing speech therapy:

'I did not visit a speech therapist when I was young, because there was no woman available who specialised in this field. More recently I wanted to see if I could [visit a speech therapist]. I entered a place and I saw the prices explicitly; I mean they were overpriced; I mean 500.'

Hence, despite Tara having managed to accept her stutter and now considering it as part of her identity, she is pursuing stuttering treatment regardless. Nevertheless, Tara's access to treatment from a male speech therapist has been obstructed by social norms. Additionally, Tara is posed with a financial barrier of inflated prices, believing them to be unreasonable for the service being offered. However, although Tara was unable to visit a male speech therapist while younger, she is currently a medical college student where female students interact with male teachers and peers. This possibly indicates a positive change in Saudi Arabian societal norms.

Participant Al-Anood's fears of being judged prevented her from seeking stuttering treatment. Despite Al-Anood noting her desire and need to visit a speech therapist to facilitate her coping mechanisms and to reduce her stuttering, Al-Anood was unable to do this due to being concerned about her personal information's privacy and the risk of it being acquired by other people who know her:

'After I got married I searched for speech clinics, although so far I have not gone to any clinics because I live in a very small area, so everyone here knows each other. I am fearful that if anyone knows that I am visiting a speech therapist they may tell my family and my relatives, which could embarrass my husband and me. Therefore, I want to visit a clinic that I can trust.'

Al-Anood's narrative makes it apparent that a negative aspect exists in relation to residing within a strongly connected community, wherein individuals' privacy may not be respected. Due to Al-Anood's social and cultural environment, visiting a speech therapist has not proven straightforward. Such challenges may derive from Al-Anood's perception of what others' perspectives of her and her husband might be if they were aware that she was visiting a speech therapist to treat her stutter. Social barriers will be further discussed in Chapter 7.

## **5.10: Summary**

This chapter has considered how the participants perceived their lived experience of stuttering. The analysis resulted in the emergence of nine themes, all of which were linked

to stuttering's effect on the PWS themselves and on their lives' educational, professional and social aspects. Such an effect was described by the participants, who related stories and events that had happened to them and which contributed to their perceptions of stuttering's effects in varied contexts. Furthermore, the participants clarified what the stuttering concept means to them, through describing how they feel when they stutter and its effect on their ability to engage in social communication, as well as say what they want to say.

The key point emerging from all of these themes is that stuttering experiences vary across individuals; even if there are similar events, the way PWS derive meaning from such events may be affected by personal aspects or other events. PWS' perceptions of their stuttering experiences were markedly affected by their personal interpretations, alongside how they derived meaning from the events occurring during their lives. Thus, they typically reformulated their understanding of stuttering's causes and its associated concepts, in addition to their observations regarding how stuttering had affected their lives, through drawing on their previous and current experiences of living with stuttering.

Because life stories comprise of a set of events that have been collated to mould one's life story, some positive events following on from difficult events may facilitate the restructuring of a positive perspective. Essentially, the meanings PWS derive from their experiences could be associated with the process of understanding their environmental interactions, which may pertain to their social interactions as life events that have contributed to moulding their self-perception as stutterers as well as the understanding of their surroundings. This includes their social relationships, for instance with their families, peers and society. Consequently, it was significant to focus on how participants described the events, what they said about them, in addition to how they perceive these events' effect on themselves and their current lives. The following chapter focuses on how the participants reconstructed their overall life stories.

# Chapter 6: Findings Part 2: What Type of Narrative do PWS Adopt When Reconstructing their Life Stories?

This chapter concentrates on comprehending *how* participants reconstructed their life stories, aiming to explain how they perceived and interpreted their overall lives as being affected or unaffected by stuttering. Additionally, an investigation of the language they used to convey their personal role in controlling stuttering's effect on themselves was made. Consequently, this section differs from chapter 5, which concentrated on participants' stories and the events they lived through. Some of these accounts were painful for the participants (see ethical considerations, Section 4.9), however, this chapter analyses the overall narratives to which these accounts related to. The analysis reveals that the narratives are more complex than some of the themes arising from the life stories might suggest.

The types of narrative are presented in paragraphs through choice selected quotations taken from the participants' narrated life stories, alongside particular participants' visual materials comprising information that was connected to their presented narrative type. Therefore, not all of the visual materials included by the participants are presented below, rather it is just the visual material with relevance to the types of narrative being presented. However, a full set of the visual material and their interpretations are appended on Appendix G (page 295). Participants reconstructed their life stories in accordance with three main narrative types: Narrative of Difficulties and Challenges; Narrative of Acceptance and Transcendence; Narrative of Conflict and Multiple Selves (Table 6.1).

Table 6.1: The Type of Narrative PWS Adopted when Reconstructing their Life Story

<b>Narrative Type</b>	How it was conveyed
Narrative of	Participants adopted language (including samples and words) that
Difficulties and	provided the meaning of negative impact from past and current
Challenges	adverse experiences. For example, 'pain', 'oppression' 'injustice'
	and 'I cannot forget'.
Narrative of	Participants adopted language (including examples and words) that
Acceptance and	suggested managing to accept living with their stutter and its varied
Transcendence	consequences. Moreover, their language indicated that they had
	overcome previous and present difficulties. For example, 'I said yes
	I have a stutter' and 'I accepted the idea of having a stutter'
Narrative of	Participants adopted language that gave the meaning of having more
Conflict and	than one self, with participants facing a conflict between these
Multiple Selves	selves. For example, 'the stuttering personality and the 'individual's
	actual personality'

## **6.1: Narrative of Difficulties and Challenges**

The narrative of difficulties and challenges presented the PWS' tough experiences pertaining to the adverse consequences of living with stuttering, alongside their perception that nothing apparently can be done to overcome, come to terms with or forget these experiences. Arguably, an individual's extent of difficult feelings may be significantly determined based on the individual meaning they assign to their stories (Corcoran & Stewart, 1998). Despite most participants' providing narratives conveying stuttering's deleterious effect on their lives, nine of the 16 participants evidently related a narrative of difficulties and challenges throughout their storytelling (Table 6.2). Mohammed and Rakan related how they had not succeeded in forgetting their childhood bullying experiences, while Sarah, Abu-Abdullah and Al-Anood pointed to their difficulties stemming from limited self-acceptance. Ali and Yasser connected their enduring difficulties to their social communicational problems throughout their life, whereas participant Fahad and Kholod's difficulties stemmed from their disclosure challenges. Accordingly, four principal themes were identified under the narrative of difficulties and challenges: Lack of Self-Acceptance; Disclosure Difficulties; Past Social Difficulties; as well as Childhood Difficulties (Table 6.2).

Table 6.2: Themes Related to Narrative of Difficulties and Challenges

Participant	Lack of self-	Disclosure	Past social and	Childhood
	acceptance	difficulties	academic	difficulties
			difficulties	
Abu-Abdullah	✓			
Sarah	<b>√</b>	✓		
Al-Anood	<b>√</b>			
Kholod		<b>√</b>		
Fahad		<b>√</b>		
Yasser			✓	
Ali			✓	
Mohammed				<b>√</b>
Rakan				<b>√</b>

## **6.1.1:** Lack of Self-Acceptance

Three participants, namely Abu-Abdullah, Sarah, and Al-Anood, narrated enduring difficulties due to having still not accepted living with a stutter. However, they expressed a desire to overcome their stuttering, which has resulted in their concentration on their stuttering experience's negative aspects, feeling that they are unable to enjoy their lives

prior to overcoming their stutter. Participants Abu-Abdullah and Sarah emphasised their concerted desire to overcome their stutter, because having a stutter has negatively affected their lives:

Abu-Abdullah clarified how he has experienced a sense of difficulties since the onset of his stuttering until the present period. Moreover, Abu-Abdullah clarified that stuttering has been his sole and profoundest obstacle which he has been unable to overcome:

'I suffer from stuttering, and I want to be cured, by all means. Whatever it takes, I want to be cured'.

#### He also stated that:

'The severity of my stuttering increased until it became my only problem that I could not overcome'.

Abu-Abdullah's speech conveyed how living with stuttering has involved him suffering, as clear from his use of the word 'suffer', words such as 'my only problem', alongside his sense that he feels he is unable to overcome the stutter. Having evaluated how Abu-Abdullah spoke, as well as having connected his words and sentences concerning his feelings of the difficult experience, it is evident that his feelings about stuttering and his desire to overcome it were strong. Furthermore, he has been unable to cope and accept his life with stuttering, which possibly exacerbated his adversity.

Similarly, participant Sarah related her belief that there is no method for treating her stutter. Furthermore, she considers that her life would be better if she did not stutter, because of her negative thoughts related to stuttering and the harmful events she has experienced having affected her life. On this basis, Sarah perceives her stuttering as meaning she has missed out on crucial life experiences:

'I always think that if I did not stutter then my life would be different [...] If someone said to me, we will take everything from you and give you fluency of speech I would accept, because I feel that I have missed a great deal due to my stuttering'.

Consequently, Sarah disclosed her overall evaluation of her life with stuttering, while imagining her life without it. She concluded her evaluation by expressing the belief that her life would have been significantly improved without her stutter; indeed, she is prepared to sacrifice everything to gain fluency of speech.

Participant Al-Anood discussed her dearth of self-acceptance, while she blamed herself for continuing to be affected by her stuttering. Al-Anood initiated her life story by indicating that her stuttering experience resulted in her development of a negative self-attitude. Ultimately, Al-Anood blamed herself for her stuttering and associated anxieties. She elaborated by explaining her uncertainty regarding whether she would develop greater self-acceptance of living with her stutter:

'When I think about myself, I feel I am not emotionally stable. I blame myself; I always think negatively, I always blame myself, and I have no self-acceptance, I don't know why'.

Al-Anood related how she has spent time on introspection concerning her life with stuttering, being unable to identify any way in which she might accept her stutter and cease blaming herself for negativity over her stuttering. On this basis, the manner in which Al-Anood interpreted her life story—discussing this particular issue at her narrative's outset—potentially indicates that her self-blame and insufficient self-acceptance might have affected Al-Anood's self-perception of her sense of enduring difficulties during her stuttering experience. Ultimately, if Al-Anood, Abu-Abdullah, and Sarah ceased blaming themselves and accepted living with stuttering, they might ultimately perceive a more positive stuttering experience.

## **6.1.2: Disclosure Difficulties**

Participants related how they faced difficulties with discussing their stuttering with others. Participants Kholod, Sarah and Fahad clarified how they confront disclosure difficulties, preferring not to discuss their stuttering with others. Participant Kholod's narrative potentially shows the connection between the level of disclosure and self-acceptance; disclosure difficulties result in limited self-acceptance, which subsequently affects one's ability to live with stuttering. Kholod has ultimately realised that her most profound problem is her inability to accept her stutter; she is entirely reluctant to discuss it with anyone. People who know Kholod do not even attempt to discuss her stutter around her, given that her discomfort becomes apparent on her face and in her body language, as well as her apparent loss of self-confidence:

I strongly dislike it when anyone asks me about it. The look on my face shows my feelings [...] I am very sensitive about this [...] I think perhaps I haven't overcome my stutter until now, because I've been absolutely unwilling to discuss it with others.

The principal theme running through Kholod's life story until the present has been her sensitivity to any references to her stutter within social contexts. Since childhood, Kholod's stutter has been a constant source of acute embarrassment for her. Even during the early stage of her life, Kholod's peers would enquire as to why she spoke the way that she did; this just continued as she entered adulthood. Even today, now that Kholod is a teacher, people ask her: 'Isn't it a problem to teach when you stutter?' Regardless, Kholod appeared to believe that discussing her stutter herself might assist her with overcoming it to a certain extent, alongside her resultant embarrassment. Kholod believes that through discussing her stutter, she confronts her problem and might ultimately come to terms with it. Additionally, Kholod related her sense that self-confidence might support her in overcoming her stuttering, therefore enabling her to resolve the numerous challenges she has experienced during her life.

Sarah experienced further complications and unusual feelings while discussing her stutter with her therapist, recalling how she spent the majority of the session time crying:

'I visited a speech therapist and I was alone; it was one of the oddest feelings in my life when I started explaining to him, I was crying all of the time'.

Sarah expressed how she felt sensitive discussing her stuttering, even with a speech therapist. This is possibly an outcome of Sarah having disclosed her stuttering's negative impacts while spending time with the therapist, thus making her visit so emotional. Additionally, Sarah noted that she preferred not to discuss her stuttering with anyone, even her family and cousins:

'I had a bad feeling when one of my cousins sent a video on WhatsApp about stuttering and its treatment. He intended to send it to me, I had a bad feeling and I could not talk about it easily, or simply say to people 'yes I have a stutter.'

Likewise, Fahad stressed that he had not discussed his stutter with anybody prior to this research interview:

'I don't enjoy talking about my stutter with anyone, even with my family. You are the first one that I have discussed this topic with'. Participants Kholod, Sarah and Fahad explained that, generally, discussing their stuttering with others is not something they enjoy, as they still feel unable to acknowledge to others that they have a stutter. In this regard, they may not yet have attained a level of stuttering acceptance enabling them to discuss the subject with others.

#### **6.1.3: Past Social and Academic Difficulties**

Participants Ali and Yasser's difficulties concentrated on the social and academic challenges that they had experienced throughout their lives. Participant Ali suggested that the effect of negative social interactions endured for a very long time; despite having forgotten the stories and their details, he continues to recall the negative feelings associated with them from these negative social interactions.

'I doubt whether I will ever forget the suffering this caused me, and the consequences will follow me throughout my life. Even though the situations are just memories now, their impact is real and remains part of my life story.'

## Furthermore, he explained:

'I can't remember these things in great detail, but I do remember how they affected me and this is the most important memory.'

This may indicate social experiences' significant role in shaping Ali's understanding of his life experience of stuttering. Ali might have been especially affected by adverse social interactions, or he might think and recall negative experiences more often than positive experiences. Otherwise, positive experiences might be considered by Ali to be something 'normal' and therefore forgettable, whereas negative experiences are more memorable.

Similarly, participant Yasser's narrative stressed the detrimental aspects of his stuttering experience, including speech difficulties, society's negative influence, alongside unhealthy relationships with his teachers and peers during his time as a student. Alongside Yasser's explanation of how such aspects detrimentally affected him, (Figure 6.3).

Figure 6.3: Yasser's Visual Materials

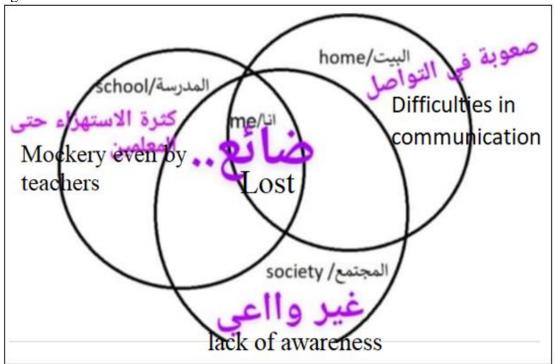


Figure 6.3 shows that Yasser placed himself central to his diagram, writing 'lost'. Therefore, Yasser explained he felt lost in the centre among societal, school, home and everyday life factors. He said that the above table was a good way to represent his life story. Moreover, Yasser related how he has confronted obstacles during the pursuit of certain activities and goals because of his stuttering, thus exacerbating his sense of loss. Society, school and home were the components Yasser presented in the table, selecting terms that summed up the negative perspectives and challenges linked with each factor. 'Insufficient awareness' was how Yasser summed up society; regarding school, both educators and fellow students abused and mocked Yasser, while he associated communication challenges with his home life. Nevertheless, throughout his academic experience, just one educator inflicted abuse on Yasser, although this teacher's taunting features prominently in the chart's depiction (Figure 6.3). Consequently, during the stuttering life story's formulation, a significant effect of negative experiences is apparent. Accordingly, broader society's insufficient knowledge of stuttering, his school life, Yasser's interaction with educators and fellow students, alongside family life communication difficulties, all affected his self-perception and stuttering-related adverse experiences.

### **6.1.4: Childhood Difficulties**

The enduring effect of childhood difficulties was the narrative type adopted by two participants. Mohammed and Rakan reconstructed their life stories around the profound detrimental effect of enduring difficulties resulting from the childhood bullying and insufficient family support they had endured. Mohammed's narrative of difficulties indicated that he continued to face numerous challenges related to his childhood experience. While, Rakan expressed his desire to support children who stutter.

Mohammed explained that he remains locked in a struggle with the past, feeling he is unable to overcome his experiences and move forward in his life. To a greater extent, he perceived himself as a victim. He believed that his feelings related to past experiences which had a profound effect on him during childhood, as well as during adulthood. Mohammed stated:

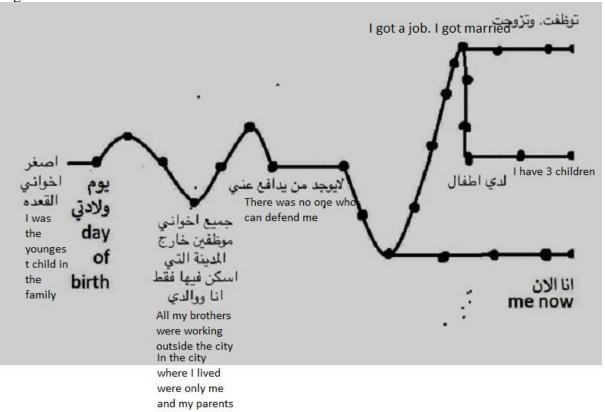
'I experienced so much pain, oppression and injustice that it severely affected me at school. I would just cry, like I am now. These childhood memories still make me sad to this day and I cannot forget them.'

### He explained further:

'When these things happened, I did not try to defend myself. I often wonder, if I had fought back, maybe my childhood memories would not be so bad [...] in fact these childhood memories are still similar to what I experience now.'

Consequently, as a 40-year-old, Mohammed states he has been unable to overcome the negative events that he experienced during childhood. He states that he continues to feel the same undiminished pain from the time that the bullying actually occurred. From Mohammed's narrative, it may be the case that when he recalls himself as a bullied child unable to defend himself, he remembers the entire scene and scenario. As Mohammed indicated that he experiences the same feelings repeated again, as if the events were occurring in the present. Mohammed said that these feelings make him wish that he could return to his childhood with his current strengths, in order to help his childhood self. The visual material provided by Mohammed explains how he perceived his childhood experience (Figure 6.4).

Figure 6.4: Mohammed's Visual Material



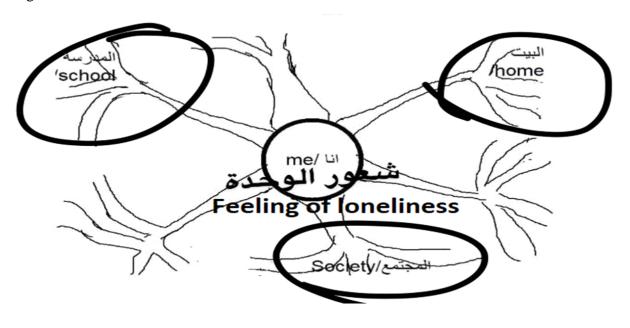
Mohammed explained that he opted to depict his life story in the above manner (Figure 6.4) because of perceiving his life experiences as fluctuating; sometimes up and sometimes down. Mohammed wrote his negative childhood experience on the down line, reflecting his experience at home due to being alone and lacking any support. He was the youngest child in his family, living alone with his parents after all of his brothers left the city. This resulted in him stating he had insufficient support, because Mohammed had nobody who could help defend him when being bullied or mistreated. Accordingly, an analysis of Mohammed's chart evidently shows how his childhood period and experiences shaped his life story most significantly. In contrast, on the higher lines Mohammed wrote about his securing of employment, getting married and having children. Thus, it could be stated that his perspective of his life experiences changed positively when he strengthened his social position by securing a job and getting married, thus reflecting social norms.

Similarly, Rakan still recalled his childhood feelings of loneliness, believing that he has had to deal with his stuttering alone without any support. Yet, Rakan said that he wants other children to avoid experiencing the same feelings that he had. Rakan stated that whenever he meets a child who stutters, he recalls his own childhood experiences:

'My aim now is to help poor children who stutter, to prevent them from experiencing bullying and assist them in not living in isolation and loneliness. I saw a child who stuttered and the man who was working as a cashier bullied him. That child reminded me of myself; when I see any child suffering, I remember myself, and I wish and ask God to prevent them from facing trouble, because when the person is a child they will suffer.'

Rakan concluded his life story by referring to his childhood, which provided a sense that presently, he is reflecting on his childhood feelings and experiences. Consequently, having discussed his stuttering awareness, as well as his school and career experiences, Rakan returned to relating his childhood challenges and expressed his concern over children who stutter; Rakan wants them to avoid undergoing similar experiences to his. In this regard, Rakan appeared to understand other PWS' feelings, given that he shared similar experiences and feelings with them. Moreover, childhood memory comprises a significant component of Rakan's life story, potentially indicating his childhood experiences' profound effect on his feelings. He was small and weak during that time, rather than the strong adult he is currently. Rakan added that he would like to convey a message via this research, as a means of raising the significant issue of providing children who stutter with sufficient social support. Rakan's visual material depicts and represents his difficult childhood, alongside the loneliness that he felt (Figure 6.5).

Figure 6.5: Rakan's Visual Material



Rakan explained that he selected this diagram because he perceived every element, whether home, school or society, as being generally responsible for people's stuttering. He believed this to be true concerning his personal experience, especially during his childhood. Rakan chose this diagram because he considers himself to have lived his stuttering experience alone, largely receiving no support from the three elements of home, school or society. Now aged 57, Rakan explained that during his childhood, nobody from his family or school discussed stuttering with him and nobody sought to assist him. He suggested that people in his surroundings might have expressed sympathy at times, yet he received no genuine encouragement from anyone. Rakan clarified that nobody would say to him, for example, 'live your life, you are normal'. He attributed this absence of support from people to their dearth of awareness and knowledge during this time. Nevertheless, he understood this and excused them. Rakan explained that while he was growing up, the situation was markedly different from the current context, where knowledge and education regarding stuttering are far more pervasive. Ultimately, Rakan believes that if he had been provided with the requisite social support, he would not have endured all of these stuttering-related challenges and uncertainties alone.

Therefore, through Rakan connecting his childhood narratives with his present concern over young children who stutter, it is possible to understand how Rakan continues to recall his personal childhood difficulties yet is seeking to move beyond his personal situation. Rakan wants to think about how he can prevent children who stutter from undergoing the same experiences as he has. Thus, he became increasingly concerned with supporting such children. This may be a consequence of his difficulties during childhood, or/and his recollection of himself while younger and possibly weaker. Meanwhile, some older PWS may feel that they have overcome and been released from their difficulties because they have simply finished the stages of their life that they deem to be significant, in terms of shaping and determining their future lives.

Rakan's words are highly significant with regards to how his worries have shifted over time; now aged 57, there is a greater likelihood that Rakan has overcome his childhood and adolescence-related difficulties. Consequently, Rakan's present concerns are not related to anxieties regarding his personal circumstances, rather he is concerned for children who are presently enduring the challenges that Rakan previously confronted. Therefore, his life story's principal focus is to convey how his personal problem with

stuttering was ended, with his primary concern being the provision of support to other PWS, especially children who stutter. This suggests that older people possibly have a greater likelihood of overcoming and being released from some of their life's difficulties by a certain age (Bricker-Katz et al., 2010). Afterwards, they might be able to make more concrete decisions concerning difficult aspects of their life, for example education, securing a career, marriage and so forth.

Thus, age might have contributed to Rakan adopting the narrative of transcendence, because he is beyond the age at which people are reliant on their families, or influenced by other people such as their parents and teachers. Moreover, he had finished university, got a job and married. Comparatively, the majority of participants were relatively younger and remained in the process of working to shape their futures, with most still being university students, or looking for jobs, or still dependent on their families, or still confronting workplace difficulties. Therefore, they might continue to consider the effect of their personal experience of stuttering. Therefore, they might feel the personal need to overcome their stutter's negative consequences as a means of fulfilling their lives' coming stages, before they reach the level at which they might focus on supporting more vulnerable people (PWS' age and feeling of transcendence is discussed in Chapter 7).

In summary, those participants who adopted the narrative of difficulties and challenges did so because they related this narrative to their existing feelings regarding their previous adverse experiences. Ultimately, certain PWS were still unable to accept the idea of having a stutter, or could not even discuss it with others. Such participants suggested that their difficult experiences continue to be a present concern for them. However, one participant adopted language which suggested that, regardless of their difficult childhood experiences, they are no longer concerned about their personal problems, instead seeking to support other PWS who are struggling with social challenges.

## **6.2:** Narrative of Acceptance and Transcendence

Seven Participants reflected the narrative of acceptance and transcendence, with their acceptance of living with stuttering connected to four principal themes: Self-Acceptance; Life Achievements and Positive Challenges; Having a Role Model, as well as Faith. These are considered to have encouraged the participants to perceive their experiences

positively, while Faith concerns participants' spiritual experiences of their relationship with God, some participants expressed more than one cause of their self-acceptance, as summarised in Table 6.6.

Table 6.6: Causes of PWS' Self-Acceptance

Participant	Accepting the stutter	Life achievements and positive challenges	Having a role model	Faith
Tara	✓	✓		
Fajer	✓	✓		<b>✓</b>
Haifa	✓			
Alia	✓			
Maha	✓		✓	
Omer		✓		
Rakan		✓		
Baraa				✓

### **6.2.1: Self-Acceptance: Accepting the Stutter**

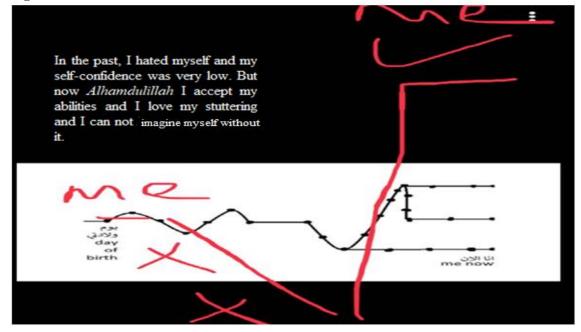
Three participants, namely Tara, Fajer and Maha, spoke about how they have managed the self-acceptance of their stuttering as an aspect of their personalities. The participants clarified how they saw a positive effect once they had developed self-acceptance, with such self-acceptance also deemed to have enhanced others' reactions and responses. Participant Tara accepted her stuttering as an aspect of her identity, which according to her is not something that should be considered a problem affecting PWS' lives. Tara clarified how she no longer deems her stutter to be a problem, as it is a central component of her identity and daily life. Moreover, Tara advised other PWS to believe in themselves and their abilities, in addition to avoiding using their stutter as an excuse for underachievement:

'Now I feel my stuttering is not an issue. I believe that people who stutter are highly talented and possess significant abilities, although the first step necessary for them is to love themselves and have confidence in their abilities, perceiving themselves as extraordinary individuals.'

In this regard, Tara conveyed a profound analysis of the relationship of stuttering to her life choices, explicating her position that stuttering should not be viewed as a hindrance or excuse for underachievement, on the basis that PWS are capable of everything. Tara stressed her belief that once a person accepts their stuttering, it will not post any barriers to their life attainment. Additionally, Tara emphasised the notion that stutterers are

'normal' people, whose stuttering should not be deemed a problem. As Tara depicted on the timeline in Figure 6.7, the red line represents improvements in her self-confidence and self-acceptance:

Figure 6.7: Tara's Visual Material



The above timeline illustrates how Tara's experience was enhanced once she developed self-acceptance. Tara has passed through three main life stages. As she clarified in the words she wrote at the top of the chart (Figure 6.7), her early life and childhood were average, being neither negative nor positive. Subsequently, she endured negative life experiences corresponding to the line Tara depicted as a steep decline on the timeline; her lowest points as the very worst times of her life are indicated by two X's. Following this, Tara drew a steep rising line to the highest point, marked with a  $\sqrt{\ }$ , which Tara located as her current situation. Tara elaborated how previously, she hated herself and her self-confidence was especially low. Contrastingly, Tara possesses a strong level of self-acceptance in her present state; indeed, Tara loves her stuttering and cannot imagine herself without it. Thus, the timeline evidences that Tara's life experience was strengthened markedly after she started accepting her life with a stutter.

Meanwhile, Participant Fajer noted that self-acceptance has enhanced her stuttering experience: Fajer explained that having accepted her stuttering and ceased being concerned with other's opinions, her stress and stuttering declined:

'When I accept to live with stuttering and I simply ignored other people, my stuttering would disappear like a magic.'

Fajer's words illuminate the positive effect that stuttering acceptance and ceasing her search for treatment had on her stuttering experience. These improvements might have stemmed from the diminished stress and pressure she might have felt which had stemmed from unhappiness with her stuttering. Additionally, she has disregarded other people's comments and perspectives, which also proved significant in reducing her stress because she no longer cares about others' opinions. On this basis, Fajer does not mind stuttering in front of other, which in turn has reduced her stuttering.

Similarly, participant Haifa's visual material conveyed how acceptance of stuttering reduced her stutter's negative effect (Figure 6.8):

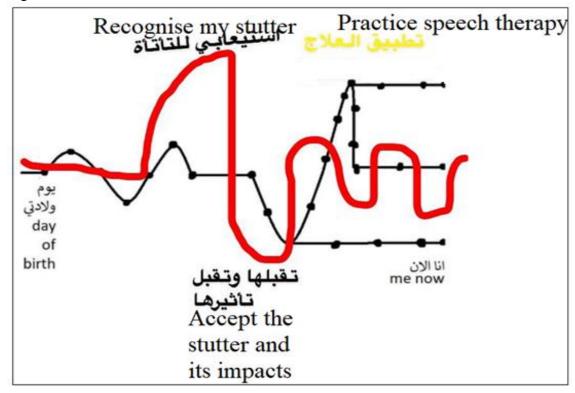


Figure 6.8: Haifa's Visual Material

Haifa selected the above timeline (Figure 6.8) to present her life story. Nevertheless, she amended the timeline's original shape; she opted for a red-coloured line amendment to reflect her own life. Haifa drew a straight line from her birth and early childhood, with the red line subsequently climbing to its highest point; she clarified that this represented her stutter's negative effect when she first recognised it and was engaged in social

interactions. Haifa recognised her stuttering as being a result of her negative social interactions. The timeline's lowest point is connected to Haifa's acceptance of the stutter and its effects; she sought to convey how, at the point when she accepted the stutter and its effects, the line declined as a means of representing that her stutter's negative effects had declined to their lowest level. Following this, the red line fluctuated, indicating how Haifa has confronted certain highs and lows throughout her life story. Notably, Haifa placed the aspects related to speech therapy at the top of the line, suggesting that participation in some speech therapy training has enhanced her stuttering experience.

In brief, Haifa's life story depicted through the timeline presented how her stuttering experience has passed through various levels and turning points. Haifa's most challenging period was the point at which she acknowledged her stutter, while her easiest time was having accepted her stutter. Ultimately, her life experience has been characterised by high and low periods. Nevertheless, Haifa did not offer specific elaboration on such periods. These might have been connected to the natural periods of human life, given that numerous individuals experience both negative and positive days.

Alia indicated that once she accepted her stutter, she felt released. She explicated how, once she ceased her attempts to obscure her stuttering, her strength and confidence to discuss her stuttering increased. This reflected positively on her surroundings, given the decline in bullying and mistreatment from others once she accepted to discuss her stuttering with peers:

'I just spelt it out: 'I have a stutter'. Since then I felt free to say it, I told all my friends and family about the problem [...] nobody bullies or laughs at you when you say it in a strong and confident way.'

Alia contrasted her feelings prior to and following her disclosure of her stuttering to others. Alia clarified that having stopped feeling ashamed of her stuttering and having managed to accept it, people were compelled to accept her stutter and ceased their negative comments, bullying and teasing.

Participant Maha explained her development of self-acceptance regardless of the negative stories related by her—that no support was forthcoming from her family, alongside the graver issue of being a domestic violence victim and having a negative mother—ultimately, Maha accepted that she must live with her stuttering: Maha began accepting

her stuttering during her final year of university, something which has continued into the present time. From the point at which Maha accepted living with her stutter, her self-reliance increased in terms of completing personal tasks, such as making a clinic appointment and phone calls. All of this may be deemed types of social interaction:

'I used to hide my stutter to avoid others' reactions. However, when I was in my final year of university, I started accepting that I have a stutter, saying 'OK this is not a problem'. Of course, I hope I can enhance it or reduce it, but I have personally accepted the idea of having a stutter. I started making clinic appointments independently and making calls, I go out and do my own things.'

Therefore, Maha considered her self-acceptance and acceptance of living with a stutter as being more connected to her development of an independent personality, while also expanding her social interaction. This is potentially due to Maha having ceased attempting to hide her stuttering through evading social interaction once she accepted her stutter, because she might then have been less anxious about stuttering in social contexts. Subsequently, this may have played a role in diminishing Maha's barriers to social interaction, such as her feelings of shame or desire to hide her stutter.

# **6.2.2:** Self-Acceptance Resulted from Positive Challenges and Life Achievements

Positive challenges refer to the process of PWS turning the challenges they had confronted into advantages. Certain PWS have managed to reconstruct their stuttering experience as challenges (Kathard, 2001). This study viewed this as supporting the participants with viewing their experience from a positive perspective. For example, participant Tara managed to transform a difficult academic experience into a positive challenge. Although Tara related that her foremost challenging experience was failing her oral exams, Tara viewed this as a challenge that strengthened her, thus improving her as a person:

'I could not, I was basically tense, agitated and frightened, and I was confused. Perhaps it was tension from the exam or fear, this was the reason. This was the first time I failed, it was the first time that I felt this feeling, although I was not a lazy student. I mean, this feeling of failure was painful, I mean, I broke down. However,

there were days when frankly, I feel I was strengthened by and benefitted from this experience.'

Consequently, irrespective of the myriad stuttering-related events that Tara potentially experienced throughout her life, from childhood until the present, she opted to narrate this particular story from when she was 22 years old as an event of foremost significance. This is potentially a result of the effect this event had on Tara's self-perception. Regardless, Tara deemed this negative university experience to have hindered her ability to enhance her attainment during other educational pursuits. Furthermore, Tara believed that all of her negative experiences have posed challenges that have strengthened her resilience, in addition to her achievement of greater success during life. For example, Tara has managed to perceive her oral exam failure as an experience that strengthened her personality.

Additionally, Tara suggested that her academic achievement, alongside her teachers' positive attitudes and support, significantly contributed to enhancing her self-concept and self-acceptance of stuttering. Thus, Tara considered her university education as having provided a foundation of support for her to manage living with stuttering, without deleterious consequences:

'I felt that university was the reason I coped with stuttering, because I am doing very well and all of my tutors are prefect [...] my stuttering did not disappear, I continue to stutter but I mean, I accepted it. I do not believe it will prevent me from achieving my goals, unlike what other people have suggested to me.'

Accordingly, irrespective of Tara having not overcome her stuttering, her academic achievements and the support afforded to her at university apparently facilitated her overcoming her stutter's negative consequences. Yet regardless of this university support, Tara was also a high achieving student and was accepted to study at medicine college. Thus, her tutor's support may have been effective because of Tara's own hard work, meaning that her stutter did not affect her education. Overall, Tara suggested that her college teachers' support contributed significantly towards mitigating her stutter's detrimental consequences, which subsequently facilitated her development of acceptance of life with stuttering.

Meanwhile, participants Omer and Fajer discussed their academic achievements, having broken their barrier of fear in order to participate effectively in presentations; they deemed this to be a key life turning point:

Omer recalled that his life story's turning point was when he was first required to make a presentation, which occurred during his first year of university. Omer had to decide whether he would present or not, whether he would attend the class, or even leave the university. Ultimately, Omer resolved to confront his fear and presented in front of his peers. Although Omer stuttered, he is satisfied that he ultimately made the presentation, which he recorded and noted the date and time of. Indeed, Omer considered his presentation to be a turning point, following which he began to break the barrier of fear by doing everything he had previously been afraid of doing, for example presentations, talking to people he was unacquainted with, talking to women and so forth:

'I took the decision to make the prestation [...] this was a turning point in overcoming my fears, and accepting my stutter.'

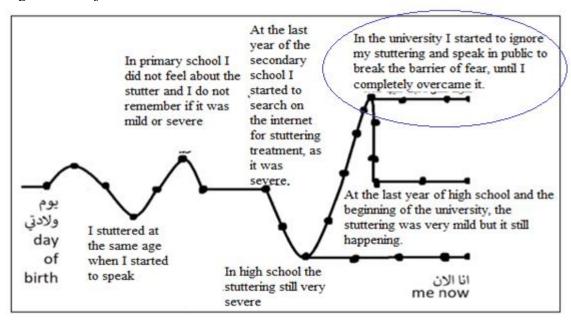
Omer decided to take a risk, presenting rather than avoiding the stressful situation. His decision subsequently encouraged him to participate more in academic and social events, despite knowing that he would stutter. Omer's life story clearly shows that overcoming his fears has positively affected his self-acceptance, regardless of not ultimately having overcome the stutter.

Similarly, Fajer's narrative of acceptance and transcendence was influenced by her academic attainment. She has had a positive experience of university, having managed to study her desired subject and having successfully participated in educational activities. Thus, Fajer aimed and managed to break the barrier of fear, through forcing herself to publicly present. Moreover, Fajer received positive feedback from her teachers:

'In the university I do not feel the stutter, and I am studying the subject I want. A couple of days ago I did a presentation. The teacher told me I am smart and that I have good presentation skills.'

Fajer's university life narrative indicates how her academic achievements might have enhanced her stuttering experience perception at university, which subsequently enhanced her self-acceptance. Therefore, although Fajer has not been able to overcome her stuttering, she has nevertheless managed to engage in an educational life that has largely avoided being detrimentally affected by the stutter. Fajer's visual material in Figure 6.9 explained how her academic achievements have enhanced her life experience.

Figure 6.9: Fajer's Visual Material



The circled part of the diagram shows how Fajer's academic achievements enhanced her stuttering experience. Nevertheless, it is important to describe the entire diagram to understand how Fajer's experience changed affirmatively through her academic attainment. Thus, within the above timeline (Figure 6.9) Fajer identified the numerous stages that she has passed through during her life. These stages are connected to her stuttering, from its emergence during her childhood and into the present period. Fajer explained that she has stuttered since she began speaking. Nevertheless, she did not feel that this was a problem during her childhood in primary school, because she could not recall her stuttering level during that time. As a teenager and while attending intermediate and high school, Fajer recognised her stuttering and began searching for treatment. Ultimately, she developed a degree of control over her stutter during the most recent period of her high school and university study.

Fajer's life story was reconstructed around her stutter's severity, as linked to her life's educational aspects. The most remarkable and notable turning points from the timeline relate to Fajer's adolescence, when she started realising that she confronted stuttering-related challenges, despite having stuttered for years prior to feeling it necessary to search for treatment. Furthermore, Fajer expressed a desire to break through her fear barrier through facing the audience at university, which ultimately assisted her with gaining control over her stuttering. This point emphasised the value Fajer placed on her educational achievements, because she opted to focus her drawing on her life story's

educational aspects compared with other life aspects such as her domestic and social contexts.

Rakan's narrative of acceptance and transcendence was related to his occupational attainment: Rakan has achieved a master's degree and has secured a good occupational career as a teacher. He elaborated that despite continuing to stutter, his career has permitted him to live a normal life; his job has enhanced his self-confidence and therefore his self-acceptance of living with the stutter:

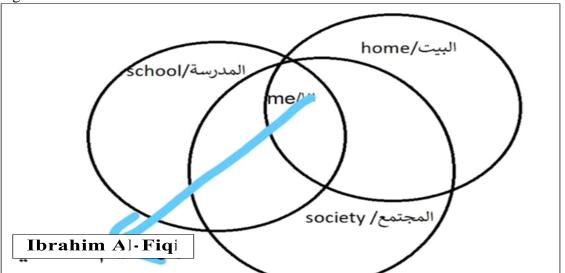
'When I got the job as a teacher, everything became normal. I have continued stuttering until now, although it is much better than before. With the improvement in my self-confidence and practicing my normal life, this has enhanced my confidence.'

Having a job can contribute to fulfilling social expectations, thus Rakan's personal life experience has been strengthened, because he has been able to live like the majority of people of his age and condition. Indeed, Rakan clarified that his job has facilitated his development of a positive self-image. Ultimately, although Rakan has continued to stutter, he does not consider it to have hindered him due to having managed to live an ordinary life; this is potentially connected to having attained financial independence.

### 6.2.3: Self-Acceptance Resulted from Having a Role Model

Maha's visual material offers some information concerning how she manged to develop her self-acceptance, irrespective of the fact that she received no support at home, given that she lived with a violent father and 'negative mother' (as she said). As Figure 6.10 presents, Maha wrote the name of a personal development expert Dr Ibrahim Al-Fqi, who she believed had contributed to improving her self-confidence. Thus, Dr Al-Fiqi was **a role model** for Maha.

Figure 6.10: Maha's Visual Material



Maha opted to present her life story in the above diagram because she considered it to accurately represent her manner of thinking regarding stuttering. She depicted herself as standing in the centre, surrounded by her family, society and school. Maha related how these three elements have exacerbated her stress of being a stutterer, due to having attempted to obscure it irrespective of whether at school, in society or with her family. She explained why she wrote the name Ibrahim Al-Fiqi as somebody she perceives as an inspirational Arab person; Maha used to watch his YouTube videos which affected her positively:

'Ibrahim Al-Fiqi affected me hugely, I decided to study Psychology just so I could become like him. [...] I felt I should write his name. I did not feel I should write any other people's names, like my father and mom; I don't believe they have had any positive effect on me, unlike Ibrahim. He made me feel greater positivity and self-development.'

Maha's explanation of why she wrote Al-Fiqi's name on the above chart revealed how sometimes, people may be affected by other individuals they are not personally acquainted with. Indeed, Maha felt more influenced and supported by Ibrahim Al-Fiqi's videos and seminars than by her own family members or other people that she personally knew in her own social circles. This may have been because of Al-Fiqi's provided content being something that Maha particularly required at the time when her stuttering started, as she sought support to manage her stuttering. Ultimately, Al-Fiqi's content might have provided Maha with the necessary support to overcome her home, school and society-related stress. Therefore, Maha valued Al-Fiqi above any other person in her life, as he facilitated her transition towards greater self-acceptance.

# 6.2.4: Self-Acceptance Resulted from Faith

Participants Fajer and Baraa connected their lives to God's will, which they perceived as having supported their self-acceptance. Fajer connected the enhancement of her self-acceptance and stuttering experience to worship. She usually asked God for help in her prayers and repeated the sentence: 'My Lord! Open for me my chest. And ease my task for me. And make loose the knot from my tongue, that they understand my speech (20 / 25-28).' This sentence appears in the holy Qur'an, being related to prophet Moses who was believed to have had a stutter. Fajer advised other PWS to use the same prayer and ask God for help.

Likewise, participant Baraa used the term *Alhamdulillah* ['thank God', or 'praise be to God'] numerous times while relating his life story, rather than complaining. *Alhamdulillah* comes from the religion of Islam and Arab culture. Baraa's tendency to thank God for everything in his life is both positive and negative, having supported him with mitigating his adverse past experiences and life challenges. For example, when Baraa blamed his family, he did not use this phrase to thank God for a positive thing, rather it indicated Baraa's discontent regarding his situation, yet his acceptance having been God's will; the event has happened, thus he is unable change it. Consequently, Baraa's narrative conveyed a sense of relief, potentially because of his problem being over, or rather because it has happened and nothing may now be done:

'I think my family should have done something to solve the problem of my stutter from the start, but Thank God.'

In this case, Barra has accepted what occurred during his childhood, regardless of wishing that his family had not ignored his childhood stutter. *Thank God* is used by Muslims to indicate acceptance of both positive and negative occurrences, as events derive from God's will. Consequently, Baraa's perspective of his life story appears to have been affected by his social and cultural environment. Moreover, Baraa used *Thank God* in reference to his life having now improved compared to the past. He possibly thinks that his life events have been solely down to God, as opposed to his own role and efforts:

'Most of these negative events occurred when I was in high school and yes, my stuttering was at its worst level at that time. But Thank God, now I am much better. I hated the teacher because he was always trying to put me down, but Thank God, now I have finished and graduated.'

Baraa did not discuss his personal achievements with regards to overcoming challenges, instead framing all of his improvements as being a consequence of God's will. Thus, Baraa's faith might have played a role in supporting his overcoming of life difficulties and previous negative experiences, therefore promoting his acceptance of the stutter and its consequences.

Overall, the participants who adopted the narrative of acceptance and transcendence while reconstructing their life stories typically situated their speech impediment as being an aspect of their self-identity. Moreover, they may have been encouraged to accept the stutter as a result of their achievements and positive social feedback. Additionally, stuttering acceptance was a self-imposed decision for certain participants who adopted a role model as well as their faith as a means of self-empowerment. Ultimately, the tone that these participants adopted while discussing their life stories was positive, indicating that they were managing to live with the stutter.

### **6.3: Narrative of Conflict and Multiple Selves**

Multiple selves is a philosophical theory (Lawrence, 2018) with its own specialist research, an analysis of which is beyond the scope of this thesis. Nevertheless, the notion of PWS' self-perception was mentioned in the literature review as being associated with PWS' self-identity as stutterers, with 'multiple selves' being adopted as a term here due to being raised initially by three of the research participants. Their words evidently conveyed this theme during the process of explaining how people should distinguish between PWS' personality with regards to their stuttering condition and their further personality aspects. The latter is considered stronger and superior in the majority of instances. This point was then deemed to be analytically pertinent among a group of participants' life stories, given that other participants explained how they experienced having multiple selves in relation to their own personalities.

Accordingly, this section is concerned with PWS' feelings of having multiple selves; one aspect of their personality is related to stuttering, whereas other aspects are related to their real personality, or a conflict between multiple selves. One self may have a tendency towards perceiving the stutter positively and attempt to live as normally as possible, whereas the other self focuses on negativity which causes inner conflicts for the person.

Three participants, namely Ali, Fahad and Alia, conveyed some narratives around conflict and multiple selves; they indicated the possible relevance of the concept of having multiple selves, which create inner conflict.

Participant Ali mentioned how a PWS might have a multiple personality; one is related to their stutter, while the other is related to himself. Ali explained that being a stutterer does not equate to possessing a weak personality and weak abilities; the problem is just with the stuttering aspect, rather than with the personal aspects in their entirety.

'Anyone who stutters is immediately seen as having these negative traits, with no distinction made between the stuttering personality and the individual's actual personality. It is of course perfectly possible that a stutterer can also be determined, motivated and powerful, but when they stutter, or as a result of stuttering, that individual presents a different side of themselves. Few people understand or make the effort to differentiate between the two aspects of a stutterer's personality.'

Participant Ali's words clearly indicate the concept of multiple selves, by arguing that people should distinguish between a PWS' stuttering condition and the other aspects of their personality, which in the majority of instances are stronger and better than the former.

Concerning participant Fahad, he discussed this intrapersonal conflict by talking about the effect on his life from negative thoughts, which fight against his positive thoughts. In this regard, Fahad expressed how his negative thoughts had detrimentally affected the path of his academic and social life. When Fahad thinks positively about his stutter, he stutters less, resulting in an enhanced educational and social life. Contrastingly, entertaining negative thoughts such as fears about talking or introducing his name, anticipating the stutter or imagining negative events that may arise—for instance feeling embarrassed in front of his teachers and peers—were viewed by Fahad as undermining his academic and social performance:

'When negative thoughts related to my stuttering increased, I became less social both in school and outside school.'

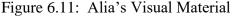
Furthermore, Fahad sought to identify another approach to support himself in strengthening his overall quality of life outside school. He aimed to do this to avoid restricting himself to his life's educational aspects, identifying a non-academic path that

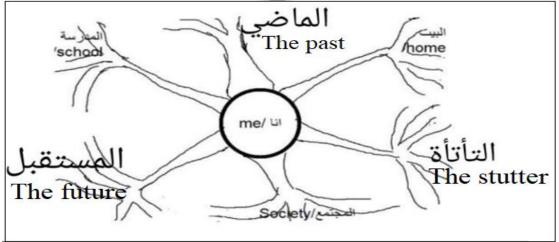
he might pursue and derive financial income from, such as becoming a football player. Regardless, Fahad conveyed how his detrimental thoughts accompanied him even away from the school environment, while his football team performance was not particularly strong. Subsequently, having been unable to determine an alternative life path outside of school, Fahad resolved to focus solely on his education. Ultimately, Fahad performed well at school, achieving the necessary overall score to attend university:

'I dreamt of becoming a football player, so I joined a team, but to no benefit. My negative thoughts spread even outside of school. Afterwards I left the team and I thought more about education. I realised that just because I could not achieve one dream, I should not lose my other dream related to education.'

Fahad's life story not only indicated his confidence in the power of his thoughts to determine his stuttering experience, it further illuminated the limited paths and life choices that people have. Additionally, a significant number of life goals necessitate either high educational attainment or extraordinary skills. This may have exacerbated Fahad's self-conflict, given that he thought both about what he wants as well as that he may be affected by external factors, for example social expectations.

Likewise, participant Alia expressed a conflict between her wanting to focus on her future, yet her mind always returning to the challenges associated with her stutter and previous negative experiences (Figure 6.11):





As presented in Alia's visual material (Figure 6.11), Alia located herself as central among the various elements; she retained the three main elements already comprising the chart, namely home, school and society. However, she incorporated three further elements: the

past, the future and the stutter. Alia elaborated how she was unable to progress with regards to her future and fulfilling her life aims, because her mind constantly returns to thinking about stuttering and the past. For example, Alia related how, whenever she aspires to overcome her stuttering, she recalls her numerous previous attempts to remedy her stutter, ultimately to no avail. Consequently, it is evident from Alia's diagram and words that numerous elements have potentially contributed to her everyday experience of stuttering in the home, school and social contexts. Meanwhile, elements that seemed more associated with her internal thoughts on such aspects as past experience and its effect on her future, may subsequently have shaped her life story's construction.

In addition, conflict and multiple selves were evident when participants' narratives were connected to more than just a single narrative type (narrative of difficulties and challenges, as well as narrative of acceptance and transcendence), for instance during the discussion of their successful self-acceptance while concurrently conveying their aim of hiding their stuttering. Potentially, this is a result of individuals having discussed their personal life stories from numerous perspectives, such as claiming stuttering acceptance while continuing to reject other people's judgements of them as stutterers. Also, some participants referred to their thoughts when they possessed strengths and weakness, while simultaneously considering themselves to have a best and worst version of their character. As certain participants clarified, fulfilling their personal demand of 'wanting to be their perfect self' potentially protects their confidence and defends against unwanted reactions, albeit costing them a degree of freedom and obfuscating their true self who stutters.

Additionally, certain participants' life stories conveyed the potential pertinence of the multiple selves' concept, with such selves seeming to result in an intrapersonal conflict. For example, one participant pursued training to enhance her self-confidence, regardless of her personal feeling being that her self-confidence remained intact, given that she felt easily able to participate in non-oral public performances (dancing). Therefore, this indicates a degree of conflict between abilities and self-confidence in various situations. The role of PWS' intrapersonal interaction on having multiple selves will be discussed in Chapter 7.

# **6.4: Summary**

Analysing the type of narrative that participants adopted was meaningful for distinguishing between the variation in experiences that PWS potentially confronted due to their stutter, as well as how they discussed the stutter's effects on their present life. Both the participants' narrated life stories, and the manner in which they reconstructed and discussed them, were strongly correlated with how they sought to deliver the impression of their overall life stories.

The crucial point generated from these findings is that participants did not necessarily report the adverse events they faced in a negative manner. One instance is how certain participants discussed their previous difficult experiences, but also suggested that they had transcended these issues and their life generally had not been detrimentally affected. Moreover, difficult experiences were occasionally valued as a positive challenge that they had overcome, thus making them a better person. On this basis, the participants' language used to reconstruct their life events can help with clarifying where the participants located and valued these events within their overall lives. Additionally, personal and social interactions are elements that potentially contribute towards shaping PWS' experiences and their perceptions of such experiences. Therefore, the subsequent chapter explores the interactional role of these variations in PWS' experiences.

# Chapter 7: Discussion of the Research Findings in Relation to the SRMD

This chapter further discusses the findings pertaining to the first two research questions, as summarised in Table 7.1 and considers them in relation to the Social Relational Model of Disability (SRMD). It attends to this study's third research question 'to what extent can the SRMD conceptualise the elements that shape PWS' expression of their life story with stuttering?'. In this chapter the commentary also draws on existing research as presented in chapters 2 and 3 in order to assess where findings concur or differ with the findings of other studies.

Table 7.1: Summary of the Research Finding

Themes for Question 1 (Q1): How do PWS Perceive their Lived Experience of Stuttering?	Themes for Question 2 (Q2): What Type of Narrative do PWS Adopt When Reconstructing their life stories?		
<ul> <li>Stuttering: The Concept and its Cause;</li> <li>Recognition of the Stutter as a Result of Social Interaction;</li> <li>The Role of Family in the Stuttering Experience;</li> <li>The Effect of Stuttering on Educational Life; Perceived School Support;</li> <li>The Effect of Stuttering on Professional Life and Career Choices;</li> <li>Participants' Difficulties during Social Interaction;</li> <li>Avoidance;</li> <li>The Impact of Stuttering on Sense of Self;</li> <li>Treatment Limitations.</li> </ul>	<ul> <li>Narrative of Difficulties and Challenges;</li> <li>Narrative of Acceptance and Transcendence;</li> <li>Narrative of Conflict and Multiple Selves.</li> </ul>		

The SRMD is adopted as the analytical lens and basis of discussion in this chapter, and its main principle is restated here. This main principle, based on Reindal's (2008) explanation, is that being a stutterer is a necessary condition that can reduce function, with this reduced function resulting in both intrapersonal and societal implications for the stutterer. Yet, whether the stutter and its effects become problematic is dependent on the social barriers that PWS experience during their intrapersonal-external interactions. Therefore, this research understands the lived experience of stuttering as resulting from

the interplay between individual and contextual influences; stuttering's negative effects result from the experience of restrictions.

Symbolic Interactionism (Plummer, 1990) is related to the SRMD with regards to how PWS' (intrapersonal-external) interactions involve meanings. Consequently, Symbolic Interactionism is adopted as a method for interpreting PWS' meaning making through their relationships with others. Such meanings contributed towards shaping their perceptions of their lived experience of stuttering, as well as the manner in which they contribute their stories to this research. The discussion is organised under three main themes: the first theme concentrates on the lived experience of stuttering, with the second theme relating to the narrative types adopted by the participants while reconstructing their life stories. The third theme discusses the stuttering concepts as related to PWS' experience.

# 7.1: How do PWS Perceive their Lived Experience of Stuttering in Relation to the SRMD?

Comparing the nine key themes (presented in Table 7.1 above) with the extant pertinent research, the Saudi participants expressed certain similarities in experience to PWS elsewhere (see Klompas & Ross, 2004; Bricker-Katz et al., 2010). However, the SRMD's adoption (Reindal, 2008) as an analytical lens during this research assisted with guiding the research through establishing, on the basis of the participants' life stories, what social and contextual barriers PWS confront during their lives. Such barriers result in various life experiences compared with people who do not stutter. The research findings indicate five barriers shaping participants' experiences: avoidance behaviours; school memories; employment stereotyping; listeners' reactions, in addition to limited support. This research's findings provide original knowledge that has received insufficient emphasis in most qualitative studies concerning PWS' lived experiences of stuttering (Isaacs & Swartz, 2020a). Accordingly, a discussion of these themes permits relevant barriers to be illuminated, while empowering PWS' voices with regards to enhancing others' awareness of PWS' experiences.

# 7.1.1: Avoidance Behaviours: Struggling in Silence

The data analysis revealed how participants perceived their lived experiences of stuttering, with avoidance behaviours established as being a crucial component of this. The results evidence that avoidance behaviours are direct effects of the stutter, indeed they are the principal hindrance exacerbating the difficulties that arise during participants' lives compared with people who do not stutter. In the SRMD (Reindal, 2008), stuttering represents the 'impairment', while the avoidance behaviours are representative of the impairment's effects. Therefore, PWS may confront communication barriers because of avoidance behaviours, not simply due to the stutter itself.

The participants' adoption of avoidance behaviours partially reflected results in the majority of studies analysing PWS' experiences (for example Kawai, Healey, Nagasawa & Vanryckeghem, 2012; Daniels et al., 2012). Nevertheless, most have identified avoidance as a coping mechanism that is adopted for self-protection from stressful situations and negative judgements (Isaacs & Swartz, 2020b; Plexico et al., 2009 a-b), rather than as being an overall life experience. Significantly, no research has investigated how PWS are struggling in silence because of their avoidance behaviours. Despite avoidance behaviours being a consequence of stuttering and social experience, struggling in silence potentially exacerbates the burden of stuttering-related problems. In accordance with the SRMD (Reindal, 2010), PWS' intrapersonal and external elements will interact and inform their experience.

Because of the interactional barrier connected to the participants' adoption of avoidance behaviours, there is reduced likelihood of them having life experience similar to people who do not stutter. All types of avoidance behaviour identified by the participants in this research, for example avoiding speaking, providing brief answers, adopting alternative words and skipping classes, pertained to the notion of struggling in silence. For instance, when some participants introduced themselves by using a different name to avoid stuttering over their real name, thus struggling in silence. By being unable to say what they actually wanted to, they remain silenced. Social interaction should result in people benefitting from self-expression and knowledge exchange, although certain PWS are unable to optimise the benefits of such interactions.

Furthermore, avoidance behaviours and episodes of silence may lead to vulnerability, through undermining others' perceptions of PWS. Others' perceptions might directly affect PWS' psycho-emotional well-being, in accordance with the SRMD (Thomas, 2004; Reindal, 2008). Certain participants who are unable to participate in the same manner as other people led them to confront others' negative reactions and judgments. For example, one participant avoided oral presentations during his team assignments, instead opting to complete the PowerPoint presentation and other preparation work. Therefore, he was subjected to his peers' negative assumptions and judgments: "Yet somebody commented, 'Yasser is useless'". His avoidance of presentations meant Yasser's peers remained unaware of his personal exertion, thus perceiving him negatively. Moreover, participants' avoidance behaviours resulted in them struggling to defend themselves, which is a further form of struggling in silence.

Hence, despite avoidance behaviour enabling PWS to evade stressful situations, such interpersonal interactions meant that they subsequently and typically developed negative self-perceptions. This interpretation reflects Symbolic Interactionism, given that Plummer (1995) asserts that people's self-perceptions may be affected by how they consider themselves to be perceived by others. On this basis and reflecting the participants' narratives, those being advised not to obscure their stutter and who were provided with encouragement, for example being told 'you are smart, you have the knowledge', fared better. The participants were supported to restrict their avoidance behaviour and were provided with reinforcement strategies and aims, which encouraged them to challenge themselves to participate. Reflecting the SRMD framework (Reindal, 2008), such affirmative social support and reassurance may assist with removing certain social obstacles to participation that PWS confront, which subsequently can positively limit avoidance behaviours.

Avoidance behaviours' effects may differ depending on social contexts and structure. Certain societal structures may result in further contextual restrictions in people's lives, according to the SRMD (Thomas, 2004; Reindal, 2008). As the findings chapter (Chapter 5, Section 5.7.4) presented, the participants perceived avoidance behaviours differently depending on the contexts in which it was accrued; when it was considered to detrimentally affect their educational and professional lives, this was deemed as a negative challenge. Meanwhile, in certain circumstances avoidance was not perceived as

being an issue, for example during family interactions or communication in specific social contexts. In numerous cases the participants did not define their behaviour as avoidance, instead explaining their activities as, 'I like to stay alone', or 'I talk little'. Alternatively, they simply clarified how avoidance was not a concern for them outside school, where their score and future achievements remained unaffected.

Avoidance behaviours may produce negative implications in terms of participants' educational or vocational experiences. For example, avoidance of participation in class activities might undermine PWS' educational performance and their future achievements (Klompas & Ross 2004; Butler, 2013b). Consequently, it may be anticipated that PWS will aim to attain their academic goals in order to achieve their utmost, which ultimately compels their participation in academic activities. Accordingly, the sorts of challenging experiences that PWS confront in school pose questions regarding why the majority of school activities necessitate oral communication skills (Blood, Blood, Tellis & Gabel, 2001). Oral examination methods can be deemed as contextual barriers in accordance with the SRMD (Reindal, 2008), which potentially undermines PWS' attainment as a result of their avoidance behaviours, regardless of the fact they might know the correct answer. Certain participants described the intense conflict they felt between participation and avoidance, due to their aspiration to be high-achieving students with the ability to enhance their performance via class participation. Regardless, they were unable to speak the requisite words. Those PWS struggling in silence may require other people's support while speaking.

The results pertaining to PWS' struggling in silence emphasise this study's significance, in terms of amplifying PWS' own voices concerning their life experiences, particularly those whose voices may be unheard. Accordingly, the life story method proved advantageous, not simply for researching PWS' experiences but also for amplifying their voices and potentially empowering them. This is especially the case for PWS adopting avoidance behaviours and hence becoming silent, because their struggles may become unobservable. Consequently, they endure a lonely experience (Ellis & Hartlep, 2017) and insufficient support. The participants conveyed affirmative self-acceptance having ceased to obscure their stutter (this issue is discussed further in section 7.2.2).

### 7.1.2: Effect of School Memories

The participants' school lives were a second obstacle to them having similar life experiences to non-PWS. All of the participants talked about their school lives, indicating their belief that their school experiences were fundamental to informing their life stories. This is because of the participants confronting societal and contextual obstacles and challenges over introducing themselves, while also confronting negative feedback. One example was participant Haifa's suggestion that leaving sentences incomplete while attempting to respond to her teachers' questions markedly undermined her positive school experience. Considering school memories via the lens of the SRMD (Reindal, 2008), particular school activities may be viewed as societal and structural hindrances to PWS' positive school experiences. Participants' academic challenges were broadly linked to stuttering during their oral tasks, such as reading, presentations and oral participation during class activities. This reflects the previous literature's highlighting of this as a pervasive issue affecting PWS' academic experiences (Hayhow et al., 2002; Daniels et al., 2012).

Furthermore, the participants clarified the severe effects of them being unable to spell out their names during their school life experiences. These difficulties resulted in certain participants skipping their first days back following school holidays, so they would avoid having to provide a personal introduction. Saudi schools commonly have students introduce themselves to the rest of their class at the beginning of academic terms, (and sometimes, discussing how they spent their holiday). The participants emphasised their aversion at having to state their names in front of the entire class, still recalling how they felt during those times.

For example, Yasser stressed that his school experience would have been more positive had stating his name not proven so difficult. PWS' anxieties around introducing their names and initiating conversations have been linked to their anxieties and avoidance behaviours in the extant literature (Plexico et al., 2009b; Corcoran & Stewart, 1998). This poses questions over the appropriateness of students having to introduce themselves in front of the entire class. Alternatively, teachers could offer alternative methods for students to introduce themselves, for example asking the whole class (irrespective of

whether students stutter) to write their names on papers or cards. Such minor changes will potentially mitigate PWS's anxiety and potentially enhance their school experience.

The participants' ability-related satisfaction can be linked to their school memories. On this basis, Hertsberg and Zebrowski (2016) observed that students who stutter presented insufficient satisfaction with their abilities. The findings of this research indicate an effect of both the participants' education difficulties and attainment, in addition to the school environment. This perspective potentially reflects the systematic literature review (chapter 3), with research identifying that school-related communication and interaction problems inform PWS' self-perceptions (Nang et al., 2018; Adriaensens, Beyers & Struyf, 2015; Boyle, 2015). Accordingly, communication and interactional challenges seem to be problems linked to school-based stuttering management, which subsequently detrimentally affect PWS' experiences. Thus, providing greater assistance from an early school age is necessary, enabling PWS to limit the attention paid to their stutter while facilitating their social engagement during school and class activities. This can undermine school barriers and enhance school memories.

# 7.1.3: Employment Stereotyping

The findings connected to participants' employment experiences evidence certain obstacles they have confronted as a result of negative stereotyping, which according to the SRMD (Reindal, 2008) may directly affect PWS' work experience. Five participants were in employment when interviewed, with four presenting narratives pertaining to their professional experiences. Concerning how the participants discussed their stutter's effect on their employment, some discussed challenges linked to completing job applications and seeking employment. Negative stereotyping might be symbolically meaningful in terms of assumptions regarding PWS' abilities. This is supported by additional literature which has observed how PWS confront negative stigma. For example, other people may assume that PWS should work in jobs that do not require speaking skills (Hayhow et al., 2002; Ellis & Hartlep, 2017). Such negative reactions might link to the symbolic meaning that individuals assign particular jobs, alongside the abilities that people deem are necessary to undertake them.

The participants in this research narrated how others expressed surprise having discovered they were teachers. This is because teaching requires a degree of speaking ability, which others might believe PWS do not possess. Those participants explained how, irrespective of the obstacles confronted, they successfully became teachers. Such findings contribute significantly to understanding how PWS respond to others' assumptions and evaluation of them. As the SRMD clarifies, others' negative assumptions may lead to individuals placing self-imposed limitations on what they can do (Thomas, 2004). Nevertheless, some participants conveyed their desire to surpass this stereotype of PWS, elaborating on their experiences in accordance with numerous perspectives while overcoming their problems and difficulties.

On this basis, some participants appeared reluctant to explore their negative or difficult experiences. This may seem surprising, because the standard perception may be that PWS' experiences will involve a degree of challenge. Indeed, this is a common literature trend pertaining to PWS' experiences (Connery et al., 2019). There was no indication among those participants discussing their workplaces that their stuttering had influenced their career choices to any degree. Additionally, each participant expressed contentment regarding their existing employment. This reflects participants' perspectives in other research, for example in Klompas and Ross (2004) where they explained that stuttering had not affected their job choices. Some of the participants in this study indicated that their stuttering has produced no adverse influence on their occupation choice or ability to secure a job. One potential reason concerns how these participants emphasised their capability to fulfil varied employment roles, including teaching and others that necessitate speaking proficiency. Ultimately, this study's participants managed to secure their desired employment and careers, thus discussing their work capabilities positively. A further potential reason for not discussing their job experiences negatively relates to participants' positive feelings as expressed during their narration, potentially linked to their career achievements which strengthened their life contentment (Connery at al., 2019).

Findings from this study indicate a need for greater public awareness and development of positive attitudes towards employing PWS. PWS are at enhanced risk of being affected by their interactions and negative employment stereotyping (Hayhow et al., 2002; Ellis & Hartlep, 2017). Moreover, reflecting the SRMD (Reindal, 2008), workplace environments can affect how PWS discuss their professional experiences. Increased

workplace awareness possibly limits negative attitudes that undermine PWS' experiences (Nang et al., 2018). One significant aspect of this present research is its illumination of participants' narratives of success pertaining to their vocational attainment, as opposed to stressing their challenges. The latter may exacerbate stereotyping of PWS rather than strengthening support for them. The participants presented examples of how their motivation to work in certain jobs and prove their abilities emerged, while simultaneously evidencing how their stutter has not hindered their performance. Consequently, PWS' success in being treated equally to non-PWS is reliant upon their knowledge and full skills-set, rather than just their speaking skills. Subsequently, this might strengthen their quality of life (Bricker-Katz et al., 2013).

### 7.1.4: Listeners' Reactions

An additional hindrance facing the PWS participants regarding their engagement in affirmative social experiences relates to their listeners' responses. This is underpinned by the SRMD (Reindal, 2008), with PWS being affected by the social obstacles they confront during interaction with others. This is due to PWS having a greater likelihood of perceiving negative reactions from listeners (Klompas & Ross, 2004). Such negative listener reactions can lead to PWS limiting their social interactions (Constantino et al., 2017). Particular participants detailed the effect of listeners' negative reactions while they were talking, including their facial expressions such as staring or averting their eyes. While these two responses appear contradictory, they both reflect listeners' apprehension, discomfort or sympathy. All of these listeners' reactions were perceived negatively by the participants, who simply wanted other people to listen in the same way they would anybody else.

The participants acknowledged these social problems' significance with regards to influencing their general experience. Certain participants explained that as teenagers they were more sensitive to others' negative feedback. However, other participants noted how their resilience was increased as a result of continuous negative interactions and feedback, including hurtful words and mockery, which ultimately ceased affecting them. The participants expressed that resilience was connected to their acceptance of negative stuttering-related experiences, as well as people's insufficient awareness. Those participants' intrapersonal thinking in relation to acceptance of others' negative reactions

and attitudes, might have fortified their ability to mitigate the effect of these negative reactions. Consequently, during this period where it is meaningful to enhance public attitudes towards stuttering, and support PWS with managing and coping with the array of people they are likely to interact with. PWS' ability to cope with others' uninformed reactions and misunderstanding could develop with time and experience (Plexico et al., 2019). Through doing so, PWS acquire the capacity for self-protection against being easily affected by other individuals (further details are presented in section 7.2.2.2). Subsequently, this should strengthen PWS' well-being and their lived experience of stuttering (Freud & Amir, 2020).

Nevertheless, the role of societal awareness in the experience of PWS is significant in the SRMD framework (Reindal, 2008), as the participants related. They explained how positive societies can enhance their social inclusion. Accordingly, PWS' efforts to avoid the effects of others' reactions may be simplified markedly if this barrier is eliminated through developing others' awareness. These results are all significant regarding the clarification of variables that complicate participants' interactions with their social surroundings. One could hypothesise that if nobody responded negatively to PWS, then the challenges they confront during social interactions would diminish or disappear. On this basis, it is recommended that people listening to PWS should aim to express no atypical responses, such as 'getting nearer' or 'looking away'. This should be the cases even if a listener is attempting to assist the person who stutters, because such reactions can exacerbate the problem, as certain participants clarified.

## 7.1.5: Perceived Type of Support by Parents and Teachers

PWS might experience contextual restrictions during their daily lives (for example at home and school), thus they typically require a degree of support. This support might diminish stuttering's negative effect (or impairment effects as they are referred to by Thomas, 2004). Via the SRMD analytical lens (Reindal, 2008), insufficient awareness among parents and educators may result in a dearth of relevant support provision. The participants discussed and appraised the assistance they had received or not received in the domestic and educational contexts, from various perspectives and meanings. Therefore, the following sections present additional discussion of the data relating to participants' perceived types of support from their parents and teachers. Subsequently,

this might empower certain PWS' voices and ensure that some of their preferences are listened to.

### 7.1.5.1: PWS' Perceptions of Families' Attitudes and Support

The findings illustrate that parents contributed significantly to shaping participants' experiences. Participants' narratives regarding their families indicate their desire to have their families accept them for who they are. Additionally, they conveyed their wish that their families had a positive attitude towards early intervention. These two points are discussed below.

Participants' evaluation of their parents' perceptions of them—either parental acceptance or lack of acceptance—affected their perceptions of themselves and their experiences. In accordance with the SRMD (Thomas, 2004; Reindal, 2008), parental lack of acceptance is considered a negative social attitude that may result in negative social interactions and experiences for some PWS at home. Blumer (1969) explained that others' perceptions of PWS, or how PWS understand others' perceptions of them, affects PWS' self-perception. Therefore, limited parental acceptance might undermine PWS' self-acceptance. As the findings relating to the participants' use of language conveyed, they sought their parents' acceptance of them as PWS. This could lead to a more conformable environment wherein they felt accepted by their family, thereby diminishing the stressful nature of their domestic stuttering experience. One instance relates to a participant's explanation of how her mother encouraged her not to hide her stuttering. Contrastingly, other participants emphasised the dearth of parental acceptance, including their feelings of sadness and shame around their child's stutter.

The participants wanted their parents to accept having a child who stutters. Consequently, parents were implored to restrain their negative sentiments, including their feelings of suffering, guilt or self-blame because of their child's stutter. This reflects the research findings evidencing how family members' expression of negative feelings regarding stuttering may undermine stutterers' self-acceptance (Leahy, O'Dwyer, & Ryan, 2012). Moreover, certain participants expressed how insufficient parental acceptance had led to undermining of their parental relationships. Subsequently, negative family relationships

can detrimentally affect PWS, due to the psychological and social obligations imposed on individuals in relation to their wider families.

Of further significance is how participants' families may also be affected by their interactions with their surroundings (Blumer, 1969), as expressed in the manner of their response to their child's stuttering. This can have a knock-on effect on PWS. Essentially, parents are potentially affected by the pressures of raising their children in a manner that accords with societal norms and expectations. For example, one participant recalled how he was told to stop stuttering by his father because it would result in negative perceptions of the family. In this instance, the father was affected by negative social reactions, thus contributing to a barrier to the father's acceptance of his child's stuttering. However, some of the parents' attitudes and emotional reactions may be shaped by their perceptions of how their children are affected by stuttering (Langevin et al., 2010). For example, certain parents could become concerned about their children's educational performance and social abilities (Butler, 2013b). Such anxieties potentially hinder parents' acceptance of their children who stutter, because they believe stuttering will affect their children. As a result, interaction between societal sectors, for example schools and families, might provide moral support for families if they feel their children are receiving sufficient support at school.

Consistent with the SRMD, insufficient support within the domestic environment may pose a social barrier affecting the way in which PWS perceive their stuttering experience. Parents who had not supported their children visiting a speech pathologist to receive treatment were negatively evaluated by the participants. They deemed their parents to have been a hindrance to the process of them transcending the problems relating to their stutter. Participants who raised this issue wished that their parents had supported them seeking stuttering treatment from a young age. This might be particularly vital regarding early intervention's role, which might have furnished participants with some assistance for mitigating their stuttering's effect (McAllister, 2016). Furthermore, if participants had at least been able to take advantage of the opportunity to participate in any form of therapy during childhood, their ruefulness as adults might have been diminished over having not pursued such treatment.

Numerous parents of PWS were unconscious of how they could assist their child (Safwat & Sheikhany, 2014), with data suggesting there is a need to enhance Saudi parents' attitudes towards stuttering. For instance, the participants in this research support early intervention, which might encourage other parents to acknowledge their child's stuttering. Numerous researchers have stressed the parental role's significance in moulding participants' stuttering experiences (St. Louis et al., 2017). Regardless, the majority of extant literature has analysed parents' attitudes towards their children who stutter (for example, Langevin, Packman, & Onslow, 2010; Al-Khaledi et al., 2009), with only a restricted focus on PWS' evaluation of their parents' attitudes towards them. Consequently, this study's significance lies in appraising parents' cognisance and attitudes regarding stuttering via PWS' own voices, therefore spotlighting their perspectives.

# 7.1.5.2: PWS' Perceptions of Schools' and Teachers' Support

Almost all participants discussed their previous school and university experiences with regards to challenges they confronted, in addition to their school and teachers' sufficient or insufficient support. Table 7.2 summarises the participants' appraisal of their schools' and teachers' support and feedback.

Table 7.2: Perceived School Support and Teachers' Feedback

Schools' Positive Support	Insufficient School Support
Did not provide special support	Lack of assistance
Prevented students from reading aloud	Educational psychologist's intervention
	Unnecessary protection
	Being treated differently
Teachers' Positive Support	Teachers' Negative Responses
Positive attitudes	Negative comments
	Mistreatment
	Openly discussed the participants'
	stuttering

The participants' perceptions as summarised in Table 7.2 have a likelihood of being based on their feelings, as reconstructed via their interactions in academic contexts. Each person constructs and assigns various meanings from their stories (Plummer, 1990; Earthy & Cronin, 2008). For example, two participants experienced comparable forms of teachers' support, namely their exclusion from oral assessments. One participant perceived this positively, having appreciated their teacher's intervention, whereas the other perceived this negatively based on her desire to be treated equally to her peers. One potential

interpretation concerns how participants might have appraised their school and teachers' support in a manner reflecting their feelings in school at the time. Thus, participants clarified their preference for equal treatment with their non-stuttering peers, due to special support making them feel that they lacked abilities. This is underpinned by Symbolic Interactionism (Plummer, 1990), which suggests that PWS' treatment in school will affect their feelings about who they are as students and their abilities. Meanwhile, further participants expressed positive sentiments regarding those educators who shielded them from stressful circumstances linked to participating in oral activities.

Moreover, this can reflect PWS' personal priorities, given that certain participants related their concerns over academic attainment and their desire to participate, regardless of whether they stuttered or not. Consequently, they wanted their teachers to permit them to participate in oral activities. Contrastingly, other participants wanted the opportunity to attain strong marks through the teacher permitting them to write their answers, because this would enable them to evidence their possession of the requisite knowledge. Therefore, no single recommended strategy should be adopted for supporting students who stutter, while teachers must also acknowledge that not every student who stutters will welcome special treatment by teachers, because this can make them feel isolated from their peers (Klompas & Ross, 2004). On this basis, providing flexible methods (Rosner, 2000) for examining students can benefit both those who stutter and those who do not, while avoiding PWS feeling distinct from their peers.

Ultimately, consistent with the SRMD, PWS may lack appropriate support at school, thus resulting in barriers to their receipt of equivalent educational opportunities to other students who do not stutter (Reindal, 2008). For example, participants' stories concerning teaching strategies and the support they receive are likely to have affected their school journey. Such strategies may pertain to examination methods and academic activities that potentially mould the educational environment. Limited research has been concerned with the classroom context, or the learning and teaching strategies that could prove stressful and uncomfortable for PWS (Daniels et al., 2012). This means that participants' narratives concerning their school and teachers' support are significant with regards to establishing PWS' perspectives of such support. Nevertheless, such findings are underpinned by personal opinions, which is a factor that needs to be considered during the application of any findings to practical work with students who stutter. Overall, it is

perhaps inappropriate to consider these personal narratives as providing robust evidence for good or bad practices that can assist PWS. Rather, they might facilitate the illumination of a more apt strategy for educators and other school employees. This could involve students who stutter being asked about their personal preferences in private, when they are not around their peers. This latter point must be emphasised, because particular participants in this research clarified their embarrassment over discussing their stutter in their peers' presence. Consequently, it might prove more effective to provide support through greater attentiveness to stutterers' personal perspectives, as an aspect of academic research concentrating on educators' attitudes. This will permit educators to apply appropriate supporting strategies that PWS themselves consider helpful, while avoiding strategies that detrimentally affect them.

### 7.1.6: Summary for Discussion of the Lived Experience of Stuttering

Understanding the meanings that participants assigned to their experiences could facilitate their empowerment. This involves listening to PWS' voices and self-perception of being affected by their stuttering, alongside how they wish to be supported. A commonplace aspect noted by the participants—which may be provided here as a recommendation—is that they welcomed others' support when it does not exacerbate their own negative self-perceptions and feelings. Accordingly, the significant finding is that it is seemingly not *what* other people do to support PWS, rather it is about *how* PWS are provided with any form of support. Other people, including parents, teachers and listeners, may need to learn how to support PWS, albeit without causing a negative impact. This may be attained via efforts to be reflective towards PWS' feelings, as well as providing them with choices in terms of how they want to be supported. This is particularly apparent in participants' narrative experiences of their home and school lives, where they received unwelcome forms of support.

This chapter's first section discussed the participants' perceptions of their lived experiences of stuttering, concentrating on the meanings they assign to the stories and events occurring during their lives, alongside how they contributed to shaping their experience. In accordance with Symbolic Interactionism (Plummer, 1990), the meaning PWS assign may alter over time. Therefore, participants' experiences shared in this study may have already been modified through their lives, from their childhood to the present.

Indeed, there is a strong prospect of them continuing being reshaped through their intrapersonal-external interactions and possibly their life stage or age. For example, a student who stutters may provide a different story to the one they might narrate following their graduation, or securing professional achievements. The following section investigates how participants reconstructed their past experiences, which may result in more effective understanding of where the participants located their stutter within their overall lives, as well as how it changed overtime.

# 7.2: Discussion of PWS' Narratives of their Life Stories Over Time as Related to the SRMD

In the SRMD, personal life experience is considered to be a social and individual construct (Reindal, 2008). Therefore, PWS' perceptions of their life stories have been informed by their lived experiences, in addition to how they react to and derive meaning from their experiences. Participants' manner of reformulating their life stories is associated with how PWS' storytelling potentially alters across various times and circumstances. Given that this research has adopted the life story/history method, the role of time and changes in life position are likely to be of fundamental interest. As the method chapter (chapter 4) detailed, the life history analysis involved contrasting PWS' present feelings concerning previous events with how they possibly felt at the time these events occurred (Rosenthal, 1993).

Consequently, the findings regarding narrative types (presented in Chapter 6) are: the sense of difficulties and challenges; the sense of acceptance and transcendence; in addition to their conflict and multiple selves. In this chapter, the participants' narratives over time are interpreted via the SRMD lens. These narratives contribute significantly to explaining the individual's role in reconstructing their realities, namely how they perceive the stuttering's effects on their current life stories. This is because PWS' life stories are constructed from their experiences, memories and narration (Rosenthal, 2006). The list below summarises the meanings of each narrative type with regards to the participants' current feelings of their overall experience:

 The Narrative of Difficulties and Challenges – the participants are continuing to have an adverse feeling associated with their stuttering experiences;

- The Narrative of Acceptance and Transcendence the participants are managing to deal with their stutter's past and current negative consequences;
- The Narrative of Conflict and Multiple Selves the participants distinguished between 'the self' and 'the self who stutters', while also appraising the conflict they felt between their strengths and weakness.

These findings involve specific elements that the participants considered to have facilitated their current enhanced lived experiences.

## 7.2.1: The Experience of Difficulties and Challenges

Nine participants related a narrative of difficulties, because they continued to confront numerous obstacles linked to their stuttering experiences. This is referred to here as a 'narrative of difficulties and challenges'. This term is adopted here in reference to previous experiences' effects on PWS' current lives, pertaining to stuttering's life effects (Koutsodimitropoulos et al., 2016). As the findings evidenced, participants' difficult experience considered as connected to both external and internal causes. This is consistent with the SRMD, given that the difficult experience is an effect of the impairment which results in both internal and external (social) implications for the person who stutters (Reindal, 2010).

When viewing these principles via the SRMD lens, external elements are relevant in relation to the participants' past social and contextual barriers. Meanwhile, internal dynamics are self-imposed factors, in terms of the participants' expressed feeling they cannot transcend their previous problems. The cause pertains to external variables within the participants' social and cultural environment, for example bullying, previous social and academic challenges, alongside insufficient social awareness and support within the family, school and general societal contexts. Such negative social experiences are commonplace among PWS (O'Dwyer et al., 2018); their social interactions begin during early childhood, a period which is considered fundamental to shaping one's adulthood (Hughes, 2007; Kathard, 2009).

Accordingly, for PWS, their experiences of being socially disadvantaged are likely to start during childhood and then endure into adulthood (Crichton-Smith, 2002). Indeed, this was the case for certain participants in this research. The participants explained how

they were subjected to mockery and bullying, reflecting the extant literature findings (see Erickson & Block, 2013; Daniels, Gabel & Hughes, 2012; Blood & Blood, 2004, 2016; Yaruss, Murphy, Quesal & Reardon, 2004). These researchers evidenced that PWS have a greater likelihood of experiencing mockery and bullying during their lives, with PWS clarifying how such negative experiences have profoundly affected them over the long term (Blood & Blood, 2016).

Moreover, Reindal's (2010) SRMD proposes that if appropriate support is provided, any impairment's negative effect, including those linked to stuttering, will be diminished. This study's participants narrated how their difficult experience resulted from the dearth of support they received throughout their childhood. This exacerbated the impediments they faced, such as bullying at school without having anybody they could turn to for support. This accords with Hayhow, Cray and Enderby's (2002) results, wherein participants lamented the insufficient support they received from an early age, support which might have enabled the long-term effects of their difficult experiences to be averted. Therefore, due to insufficient support, negative childhood experiences may have made that period of their life difficult and contributed to PWS' formulation of negative childhood memories. Evidently, just a single year of such memories might significantly affect their entire lives (Tudor, Davis, Brewin & Howell, 2013).

Meanwhile, the participants' role was significant with regards to reconstructing meanings of negative past experiences. This is aligned with the SRMD (Reindal, 2008), in which individuals' responses to social experience is respected. The results evidence that difficult experience may be affected by internal variables, including PWS' insufficient self-acceptance, in addition to their aversion to disclosure as a means of self-protection from any negative reactions from listeners.

Participants may be affected by their childhood experiences in numerous ways. For example, when they recalled challenging stories from their past, those who had managed to establish a sense of closure on these stories potentially suffered less detrimental effect. For instance, certain participants were subjected to negative comments and endured teasing at school, yet suggested this left them unaffected. Moreover, other participants briefly discussed the problems they confronted during childhood, abruptly ending their sentence by stating, 'thanks [to] God it is finished now'. On this basis, they may feel less

negative than at the time when the event occurred, due to having progressively managed to overcome the event while also having secured other life achievements.

Contrastingly, certain participants without any positive memories and experiences may be locked into the difficult feelings stemming from their challenging childhood. Those participants struggling to overcome their negative emotions connected to previous adverse experiences might continue reliving the same feelings they endured at the time these past experiences occurred, as if they were still happening presently. For instance, some participants felt unable to even discuss their childhood, explaining how they would become very upset if they did. Indeed, negative feelings while recollecting previous difficulties is likely typical for all humans, whereas these feelings develop as a problem if the issue is never resolved. These participants were not the only participants confronting childhood difficulties, yet they seemed to be the individuals most negatively affected. Consequently, their experiences were usually prescient when the theme concerned difficult experiences.

Indeed, the participants' difficult feelings stemming from their childhood bullying experiences are entirely understandable (Blood & Blood, 2016), while inevitably being particularly challenging to forget. Nevertheless, certain recommendations can be provided that may prove beneficial, drawing on other participants' experiences and examples who have managed to transcend their prior difficulties, thus forming positive experiences. Some participants continue to recall their especially challenging childhood experiences, despite not considering themselves to be suffering presently. Having deeply analysed those participants' life stories, it is apparent that they are no longer suffering due to having forgiven all of those people who hurt them. In this regard, one robust recommendation may be provided here as a means of aiding PWS who are striving to transcend their previous difficulties, namely that they should seek to forgive other people. Victims are unable to alter or eradicate the negative events they endured during their childhood, yet forgiveness can still facilitate the process of an individual overcoming negative feelings when they feel victimised, thus helping them move towards greater toleration of what has occurred and ultimately moving forwards in their lives (Kathard, 2003).

Despite the participants having different childhood experiences—and that one might consider whether some participants have suffered to a greater or lesser extent than others—PWS' forgiveness of those who hurt them the most can be a form of self-help, empowering them to move forwards in their lives. Therefore, it is recommended that parents and teachers aim to facilitate PWS' development of their capacity to forgive themselves and other people.

Overall, personal experiences of stuttering are fundamentally affected by the individual-social interaction variable (Kathard, 2001), meaning that external and internal variables should not be distinguished. This is due to participants' sense of difficulties potentially being an external and internal experience; external aspects possibly pertain to social problems and negative experiences, whereas internal factors are potentially associated with how such problems are understood and appraised by individuals who stutter (Reindal, 2008). The following section analyses the development of self-acceptance in relation to participants' enhanced stuttering experiences.

# 7.2.2: PWS' Acceptance of the Stutter

Stuttering acceptance was a significant variable with regards to enhancing certain participants' well-being. Three principal reasons why this sense of self-acceptance was produced are assessed in the forthcoming section. The first concerns self-acceptance in relation to attainments and challenges, while the second pertains to personal efforts related to responses to social barriers. The third reason concerns the role of faith and role models in shaping PWS' perceptions of their experiences. These three reasons reflect the understanding offered by the SRMD, due to them being linked to the effect of external variables on PWS (Reindal, 2008).

# 7.2.2.1: Self-Acceptance as a Meaning of Achievements and Challenges

The participants' attainments were deemed to have successfully enhanced their stuttering acceptance. The effects on participants from their experiences are interpretable via the SRMD framework. In the SRMD, recurrent exposure to positive social interaction may result in people developing positive attitudes towards themselves (Reindal, 2008; Thomas, 2004). Accordingly, their overall life achievements, alongside particular academic and professional accomplishments, may inform participants' effective

understanding of their personal capabilities. Additionally, those participants might have been compelled to seek external reassurance of their personal value (Blumer, 1969). Consequently, they have been able to manage their stutter's detrimental effects via strengthening of their academic and professional performance. Subsequently, this might have contributed to enhanced motivation and more successful stuttering management.

This concept was evidenced by certain participants who observed that successful work and educational experiences facilitated their stuttering management. One example was offered by a research participant, who explained that she does not personally find her stuttering to be an issue, because she has managed to study her preferred major at university. A further participant observed that having become a teacher, his life has transformed into one that any other person might experience, irrespective of his ongoing stutter. On this basis, his occupational achievement enhanced his stuttering acceptance.

O'Dwyer et al. (2018) indicate that an interconnection exists between PWS' general life events and their stuttering narratives. Therefore, eradicating educational and employment barriers can assist certain PWS with formulating improved self-acceptance (Reindal, 2008). Specifically, PWS have regularly reported a diminished quality of life, with fulfilment of their life ambitions regularly being undermined (Boyle, 2015; Everard & Howell, 2018). Regardless, this situation is not one that all PWS who have secured attainments have found themselves in, with the capacity to develop their self-acceptance and enhance their overall stuttering experience. Rather, individuals play a significant role in using their own life achievements to support their development of positive self-acceptance and motivation, thus attaining further success.

The SRMD places fundamental emphasis on individuals' role in constructing meaning from their positive and negative experiences (Reindal, 2008). Thus, particular participants reconstructed their stories to present how negative challenges may be transformed into positive achievements. Those participants with life achievements managed to transform their difficulties and tough memories into positive dynamics, referring to their problems as a 'positive' challenge. For example, one participant narrated an event of having failed her oral exam, although she perceived it positively on the basis that it strengthened her. Notably, she blamed neither herself nor her tutors, instead from that point on adopting it as a personal challenge to never be awarded another low score. Therefore, when

difficulties were considered challenges, each time the participant experienced these challenges and overcame them, this facilitated their development of a more positive self-perception, while simultaneously enhancing their optimistic feelings. This feeling was sometimes present at the conscious level, whereby individuals had taken particular decisions so as to transcend their previous adverse experiences and cope with their existing challenges, thus constructively progressing in their lives (O'Dwyer et al., 2018).

Furthermore, Rosenthal (2006) elaborated on the role that memory plays in people's narratives. Through applying Rosenthal's explanation, this manner of shifting past difficulties into positive challenges may arguably act as a consecration of an individual's memory and their existing achievements. As a result of their existing attainments, individuals are more effectively able to derive positive meanings from their experiences. This concept is potentially highly meaningful if understood by PWS and individuals seeking to support them. Indeed, such attitudes may shift the emphasis from diminishing negative experiences to accepting stuttering's negative consequences, dealing with them as challenges.

A more pervasive application of this idea has significance deriving from the fact that PWS and their supporters cannot be certain or ensure that PWS will be safeguarded from all difficulties within every social context. Accordingly, developing this notion of conceiving every challenge as an opportunity may augment the prospects of PWS considering their stutter from a more positive position. Moreover, an overarching relationship between self-acceptance and accepting negative consequences may exist. Some of this study's participants and those in other research have observed how, having successfully accepted their stutter, the obstacles they confronted seemed to diminish, due to their apprehension over their stutter's deleterious outcomes being reduced (Bricker-Katz et al., 2010). Overall, this research has focused on identifying how particular PWS might effectively reformulate their detrimental experiences as positive challenges, alongside exploring how such a process seemed to enhance their lives.

#### 7.2.2.2: Personal Efforts in Developing Self-Acceptance

Certain findings highlighted participants' efforts to develop self-acceptance, with two themes making this apparent. Firstly, their willingness to discuss their stuttering with other people. Secondly, the way in which they evaluate their social interactions. PWS' willingness to discuss their stuttering with others may be perceived as an affirmative self-attitude aimed at coping more effectively with social restrictions (such as others' negative evaluation) (Thomas, 2004; Reindal, 2008). This study's participants and those involved in other research, who had the ability to explore the subject of stuttering with others, felt under less pressure to hide their stuttering (Everard & Howell, 2018). Indeed, when a problem is discussed, it may be diminished. Further participants remarked how, when they were simply up front with others about their stutter and declared openly that 'I have a stutter', other people ceased bullying them. This is likely to be associated with the self-empowerment they derive from greater self-acceptance (Boyle, Dioguardi, et al., 2016).

Moreover, individuals are able to formulate meaning via adopting symbols for the interpretation of one another's actions (Blumer, 1969). Therefore, people who do not stutter may develop more positive perceptions of PWS if the latter appear strong and unaffected by their stutter. Furthermore, concerning bullying, bullies aim to hurt their victims, although they will be unhappy themselves if they fail to have the desired effect. Consequently, PWS with self-acceptance and who feel unashamed of their stuttering might evoke others' positive reactions. Subsequently, this can enhance their feelings and appearance of strength, because they are unafraid of stuttering and will present themselves as being unconcerned about others' opinions. In turn, this can reduce their inclination to hide their stutter (Erickson & Block, 2013).

A further research finding concerns how participants' perception of their society was connected to reduce the negative effect of adverse social interactions. Individuals' interactions with social barriers can shape their experiences (Reindal, 2008). This means that the extent of the negative effect on their lives is possibly assuaged by PWS' personalities, alongside how they derive meaning from their societal interactions. Those participants possessing self-acceptance seemed accepting of their stutter and its detrimental social consequences in their entirety, including societal problems such as adverse reactions, and insufficient awareness.

Individuals elicit behaviour's 'meaning' through establishing why somebody is undertaking the actions they are, the significance of these actions to them, followed by a response on the basis of these attributions. Thus, situations can be interpreted by people's

actions and attributions (Blumer, 1969). For instance, participant Tara did not blame her society for their negative reactions, positing instead that she should seek greater acceptance from all manner of people in society: "Not all people in society will be educated [...] and I will need to accept all different people in society". This approach may be rationalised on the understanding that once PWS realise that not everybody will have the awareness and knowledge about the stutter, they will simultaneously increase their strength and effective management of their social interactions' detrimental implications.

Such social capabilities may support PWS' social communication. Subsequently, reliance on avoidance behaviours may decline, due to them having less inclination to evade stressful situations, for example others' judgements and stigma. Accordingly, this study's results concerning participants' life stories evidence that PWS might feel a degree of responsibility for self-support, via easing the impact of adverse social interactions. This is meaningful because numerous PWS reside in societies that hold pervasive misunderstandings and stereotypes related to stuttering (Blood, Blood, Tellis & Gabel, 2003). Consequently, despite social acceptance being related to self-acceptance in certain extant research (Hertsberg & Zebrowski, 2016), this study has established evidence that an individual's positive evaluation of social interactions may be linked to enhanced their self-acceptance.

Thus, regardless of the evident social effect conveyed through the participants' narratives, the individual's role should be emphasised as central to the formulation of experiences. PWS' personal effort may enhance their stuttering experience, as stipulated in the SRMD, because the individual's role is respected in their response to social reactions (Reindal, 2008). Irrespective of research emphasising the social role in PWS' experience (for example, Bailey et al., 2015), a prominent element of the study findings relates to how PWS' social and cultural environment's effect was less significant for particular participants in terms of their ability to cope with stuttering. One example provided by a participant explained how she endured a problematic and unhealthy relationship with her family. Indeed, she continues to recall these difficult stories. Nevertheless, she subsequently clarified how she had learnt to cope with and accept her stuttering. The participant empathised with certain people who had hurt her, describing them as having a negative personality; this conveyed her acceptance of how the problem was with those

people rather than with herself. In this regard, the participant did not perceive her family circumstances as having undermined her current life. Arguably then, it is not necessarily the case that previous and current difficult experiences will affect every person's decisions in terms of their life coping mechanisms. Instead, acceptance may be influenced by the participant's choices, which inform their level of stuttering acceptance and ability to successfully progress during their lives.

Therefore, the significance of the findings is connected to PWS' development of stuttering acceptance. Indeed, stuttering acceptance could be deemed an aim of PWS in order to cope with their stutter. Evidently, self-acceptance has emerged as a prominent theme within the extant literature (see Bricker-Katz, Lincoln & McCabe, 2010; Kathard, Norman & Pillay, 2010). On this basis, when PWS thoroughly accept their stutter and its linked implications, they may ultimately embrace it as a positive aspect of their self-identity (Kathard, Norman & Pillay, 2010). This potentially enables them to accept the stutter as a positive component of their identity and daily life. The elements that have contributed to PWS' development of self-acceptance have been underemphasised in previous research.

It is notable, however, that participants' self-acceptance sometimes meant that they wished they did not stutter. This was especially apparent among the majority of participants who expressed their development of self-acceptance, who explained further their belief that their lives would have been markedly improved if they did not stutter. Consequently, self-acceptance may be unconnected to life satisfaction (Plexico et al., 2019). Regardless, self-acceptance may still enhance PWS' experiences, at least in diminishing the negative feelings generated from the stutter and its associated interactional difficulties.

# 7.2.2.3: The Role of Faith and Role Models in Shaping PWS' Perceptions of their Experiences

This study's findings convey how individuals derive meaning from their experiences, which may be related to their faith and having a role model. In this manner, participants reduced the negative effects of their stuttering through referring to faith or a role model who experienced stuttering, or somebody else who has confronted challenges during their

lives. The participants who invoked their faith expressed a level of stuttering acceptance, meaning that discussing faith's role in relation to self-acceptance can be meaningful. Faith offers a potential reason for why certain participants expressed greater positivity, as well as ability to accept and cope with their stutter. This may be connected to the religion of Islam—with religion being a social construct (Gergen & Gergen, 2008)—given that all Saudi participants were Muslim.

In accordance with Symbolic Interactionism, the meaning that PWS assign to their faith is dependent on what this faith offers them (Blumer, 1969). Primarily, it appears to provide them with power and support. Numerous participants referred to their faith in a variety of ways, for example, invoking God's assistance, or reading the Quran in anticipation this would assist them with reducing their stutter. Indeed, many participants indicated the support they derived from this, as well as that they advised other PWS to seek to do the same. Additionally, faith was interlinked with stuttering's acceptance in two ways: acceptance of stuttering due to it being God's will; acceptance based on the story of prophet Moses, who is believed to have had a stutter. The sentence that Moses spoke when invoking God's support was: "My Lord! Open for me my chest. And ease my task for me. And make loose the knot from my tongue, that they understand my speech (20 / 25-28)"

Certain participants explained their repetition of this sentence, or an aspect of it, as an attempt to overcome their stutter. This indicates that the sentence possesses a shared meaning among certain PWS. According to Symbolic Interactionism (Blumer, 1969), this sentence can prove meaningful and valuable for the participants; because Moses stuttered, the participants share a similar experience to a prophet. Moreover, Moses managed to cope with his stutter, something the participants were also aiming to achieve. Ultimately, when the participants recall that a prophet stuttered, this might make them feel special. The story of Moses relates particular methods that he adopted to control his stutter. One of these is called "sensory tricks" (Leon-Sarmiento et al., 2013), while another involves singing according to a rhythm. Similarly, participants' invocation of the Quran suggested that this provided them with greater power to control their stutter. The story of Moses appears in the holy books, making it the word of God, while it may also be considered as one of God's commands. On this basis, faith and religion may be viewed as an approach or map that anybody may adopt when they are feeling lost or lacking in resourcefulness.

If a PWS cannot find anybody able to support them, they may seek assistance through faith.

Extant research has established that having a faith offers PWS some strengths (Plexico et al., 2009b). However, Plexico et al.'s (2019) recent research has determined that faith is not necessarily a valuable coping strategy. Nevertheless, the current study has argued that faith and a relationship with God may help to mitigate negative feelings, for example self-blame or the blaming of others. For instance, one participant blamed his family because they did not help him to access treatment during his childhood, albeit relating his family's decision to God's will. This suggests he might have overcome his negative emotions stemming from having no opportunity to access treatment, through relating his circumstances to God's will. Ultimately, he believed that if God wills it then nobody (neither he nor his family) can change it. This might allow people to seek reassurance, through simply accepting the choices that have been available to them.

A further notable aspect relates to how certain participants develop their self-acceptance through a role model. Such role models may be close to the individuals, for example a mother or prominent public figure. PWS are affected by other people (Thomas, 2004), which means that having a role model can represent the internal-external methods that PWS adopt to help themselves with overcoming and dealing with personal and social barriers. One participant explained the significant influence of her mother throughout her life, due to her mother's positive personality. She emphasised that her mother has been the reason for her developing an acceptance of her stutter, while also explaining why she has not suffered. Accordingly, positive social interactions between the participant and her mother supported her with creating a positive self-perception, while providing her with a role model who can be emulated whenever she confronts a problem. Ultimately, this reflects positively on the participant's stuttering acceptance.

However, social interactions can have an influence without the PWS being in the same place or time. For example, a public figure called Dr Al-Fiqi played a positive role in enhancing one participant's personality and life, indeed she was inspired by him to study psychology. Significantly, the participant has been influenced by a role model she has never met, with Dr Al-Fiqi having passed away in 2012 when the participant was still a child. Even so, the participant still derived support via materials available online and in books. This emphasises the need for younger PWS to have a positive role model who they

can feel a degree of connection with. In this regard, one public figure discussed a topic that matched PWS' concerns, while another participant had a parent who understood their needs so they were able to provide a positive role model for their child. This specifically enhanced the participants' experiences, providing them with an information source which they could draw on to answer questions that they had, as explained by the participants. For example, one participant asked her mother about how she could respond when others mock her, whereas another participant viewed Dr Al-Fiqi's YouTube videos when she felt the need to, as these explained how she could develop her self-confidence. Although this sounds straightforward, the participants explained that it has beneficially affected their lives. Consequently, family members and teachers can provide strong role models for PWS in terms of how they can deal with difficulties.

### 7.2.3: PWS' Age and Feeling of Transcendence

In this research, this narrative type was connected to age, given that in the SRMD, the meaning of the stuttering experience various across time and shifting contexts (Reindal 2008; Blumer, 1969). The results indicate that during the process of individuals' maturation, changes in their experience perception possibly occur. PWS who adopted a transcendence narrative drew on their previous negative experiences—including their sense of adversity because of issues such as isolation, bullying and social difficulties, in addition to personal problems such as fears, limited self-esteem and so forth—in order to offer support to other PWS (Boyle, Beita-Ell, Milewski & Fearon, 2018). Despite only a single participant (Rakan) having presented his desire to support young PWS, it is meaningful to discuss due to its potential connection to the participant's life stage. Rakan was the sole participant aged over 55 and who was retired, meaning that his narrative provided an example of an older PWS' experiences. Connecting stuttering experience to PWS' age concurs with Bricker-Katz et al.'s (2010) research, which concentrated on PWS aged 55 and over, establishing that age potentially affects individuals' experiences. Given the limited number of older PWS involved this study, it may be pertinent to compare participant Rakan's narrative with those offered by younger participants.

Significantly, other participants were divided into two main groups, one of which was afflicted by narrative of difficulties, while the other group expressed self-acceptance. Certain participants who related a narrative of difficulties and challenges were aged

between 32 and 47, whereas younger participants conveyed a narrative of stuttering acceptance and coping. This might be understood on the basis of older participants remaining affected by their stuttering, meaning they expressed greater interest in participating in this study. Meanwhile, younger participants were continuing to work towards shaping their future, with the majority still studying, thus necessitating their continued efforts towards transcending their stutter's detrimental outcomes as a means of accomplishing their lives' forthcoming stages. In this regard, younger individuals and student employees typically acknowledged communication's crucial role in social interaction, with stuttering and other speech disorders potentially hindering their normal lives (Al-Khaledi, Lincoln, McCabe, Packman & Alshatti, 2009).

Therefore, those participants who were continuing to work towards their future goals have not had the opportunity to consider supporting younger PWS. This means that by a certain age, some PWS may have developed a stronger prospect of transcending particular stuttering-related challenges arising during their lives (Bricker-Katz et al., 2010). For example, they might have taken significant decisions pertaining to life challenges such as education, securing employment or getting married. Consequently, acquiring independence might have facilitated some PWS' attainment of a degree of problem transcendence during the appraisal of their stuttering experiences. However, with such a small sample the findings can only suggest this and further research focussed on the variable of age is needed to confirm this emerging idea.

It might be anticipated that certain older PWS will feel a greater alleviation of their pressures, having managed to overcome their challenges simply on the basis of having completed certain life stages; this has assisted with moulding and determining their future lives in a significant and positive manner. Despite the dearth of academic inquiry into older PWS, certain research studies have proposed that stuttering produces comparable effects on PWS irrespective of their age (Bricker-Katz et al., 2010). Even so, academic research carrying out life story and life history analysis has evidenced that people's perspectives are changeable over time and dependent on the environment (for example, Germeten, 2013). Similarly, this means that some PWS' experiences will differ or alter as they mature.

The significance of this study's findings is connected to two principal aspects. Firstly, PWS' perceptions of their stuttering experiences potentially reflect their present needs. Nevertheless, these are subsequently connected to both the past and future (Rosenthal, 2006). Therefore, it may be necessary for support providers to concentrate on assisting PWS with fulfilling those life aspects which they consider significant during the particular stage of life they are in (Bricker-Katz et al., 2010). For example, for younger PWS this may pertain to their educational attainment and job requirements. Meeting PWS' needs may eliminate barriers and enhance their lived experiences. Secondly, reflecting this narrative type, it can be proposed that greater interaction between PWS of various ages could enhance their mutual support. Accordingly, older PWS can explain their experiences to younger PWS. This could encourage younger PWS to acknowledge that their present problems will ultimately become part of their past, which can assist them with developing a more positive vision of their current life.

### 7.2.4: PWS' Intrapersonal Interaction and Having Multiple Selves

Certain participants refused to be identified by their stuttering, rather they considered their stuttering to be an aspect of the self. This may be understood through the SRMD lens, with Thomas (2004) clarifying that a person's manner of response to their experience can determine their self-perception. The participants in this study who explained that they have multiple selves did not restrict themselves within the identity of the self who stutters. The participants who indicated they had multiple selves and conflicts between their personalities, characters and abilities could be perceived as attempting self-understanding.

Few academic studies have analysed the concept of PWS' multiple selves, although O'Dwyer et al. (2018) assessed PWS' sense of self, determining that PWS occasionally feel a degree of ambiguity in relation to themselves, asking 'who am I?'. This question reveals the interaction between their various types of selves: the self who stutters; the self who aims to overcome their stutter, as well as their social self. Having accounted for this, it is possible to understand how certain participants explained their acceptance of their stutter while still anticipating being able to overcome it. These PWS are distinguishing between the self who stutters, the stutter and 'the self', or the person (Butler, 2013a).

Accordingly, they accept the self who stutters as an aspect of 'the self', which may endure or be removed without affecting 'the self'.

This point leads to a discussion of this issue as associated with stuttering as an aspect of self-identity. How would PWS respond to the question, 'who am I?' Would they identify themselves through their stutter, or explain that stuttering is not their identity? Certain participants suggested that stuttering is an aspect of their identity, whereas others even stated that they could not imagine their life without their stutter. For such participants, stuttering is an identity or simply a means of upholding their self-acceptance. Meanwhile, participants who distanced themselves from their stutter did not accept stuttering as an aspect of their identity. Overall, it is evident from the data that the majority of the participants in this study pointed to a clear distinction between the stutter and the self.

In the majority of cases, participants understood that possessing multiple selves may strengthen their stuttering experience, as it gives them the ability to see their life beyond their stutter. One participant expressed how their cognisance of possessing multiple selves could enhance their self-acceptance on the basis of enhanced self-awareness, therefore strengthening their self-image. Consequently, those PWS adopting this notion of having multiple selves might rationalise that their stutter should not impinge on other aspects of their selves. In this regard, a PWS will possess alternative selves characterised by specific capabilities without any overlap (Bhatia & Ram, 2001). A PWS might attain this understanding once PWS develop cognisance of their fortes and abilities, as opposed to feeling restricted to their stuttering self.

Accordingly, and reflecting every other human's experience, PWS may engage in an internal interaction between their multiple selves, aiming to reach an equilibrium between their strengths and weaknesses. The self that has managed to become dominant has a likelihood of determining one's personal experience; if that central self is the one who stutters, A PWS' experience will potentially involve some challenges. In contrast, if the central self is the one aiming to overcome the stutter, this could enable an individual to achieve improved self-reliance and self-acceptance, or may result in them hiding the self who stutters (O'Dwyer et al., 2018).

A third self may be indicated here, namely the social self (O'Dwyer et al., 2018). O'Dwyer et al. (2018) defined the social self as an amalgamation of the self who stutters and the self who seeks perfection. Additionally, for the participants in this study and reflecting the understanding of the SRMD (Thomas, 2004), the social self may also pertain to the self that appears to the other. This is informed by how societies (societal attitudes) perceive PWS, alongside the participants' self-perception within their societies. Those participants who distinguished their stutter from their 'self' pursue this as a means of encouraging positive perceptions from other members of their society. Nevertheless, certain participants' social self was viewed negatively by other people, who overlooked the strengths of the participants who stutter. For example, one participant emphasised that PWS should be viewed as fully capable of doing everything. Similarly, various participants discussed how others' perceptions of them do not accentuate their real abilities.

These results raise the problem of social restrictions (Thomas, 2004) and conflict that arises in relation to self-identity, namely between an individuals' self-perception and the society's perception of them. Reflecting this phenomenon, the participants' self-identity which might typically be rejected by other individuals is distinguished from the social identification of them. Examples may be pointed to here concerning certain participants who anticipated that other individuals would accept them and hold positive attitudes towards them. Some participants wanted their families to accept them as they are, while others anticipated that the wider society would ultimately develop enhanced knowledge regarding stuttering. For example, one participant narrated an event involving a taxi driver, who drove away when they heard the participant stutter, with the driver's action interpreted by the participant as a belief that he was 'physiologically unwell'. Such negative discordance between the participants' self-perception and others' perspectives of them may be a result of other people only perceiving the participant's identity as a person who stutters.

On this basis, if the presence of multiple selves' is accepted, the principal question concerns whether all PWS deem their stutter as an aspect of a self or a discrete self. Essentially, identifying where they have situated their stutter in their lives may facilitate PWS' with understanding the process of their stuttering becoming either an identity that affects them or one that does not. Regardless, the majority of research concerning

stuttering refers to PWS in a way that makes the stutter their identity. Almost all research in this field has insufficiently emphasised how the stuttering experience is simply an aspect of the wider life experience.

Contrastingly, this study posits that stuttering should not be deemed an identity, instead it is but one aspect of a single identity. This point of understanding that PWS may possess multiple selves, including the self who stutters and the self, is highly significant, indeed it could potentially alter the way that stuttering research is conducted. Moreover, researching stuttering experience within the context of wider life experience can facilitate the interpretation of potential variables leading to an exacerbation or diminishment of stuttering's effect on one's life. Therefore, the participants' voices regarding having mutable selves must be respected, not only with the aim of improving research but also as a means of avoiding the labelling and stigmatising of them through referring solely to the stuttering aspect, as if this is the only significant feature of their identity and selves. Elsbach and Bhattacharya's (2001) study findings exemplify how removing oneself from association with a damaging stereotype, or disassociating oneself in order to mitigate challenges to one's identity, are responses that people engage in.

Additionally, unwanted consequences may emerge from an unclear emphasis on the concept of possessing multiple selves. For example, one might overlook PWS' strengths and attainments unrelated to stuttering, yet which remain linked to the person themselves. Meanwhile, through the qualitative research undertaken in this study, the focus was on individuals as a complete entity, specifically during inquiry into their lived experiences of stuttering, given that an individual's experiences are indistinguishable from alternative elements informing their overall character. This comprises of individuals' characteristics, previous achievements and their social lives. Accordingly, as Giddens (1991) proposed, discussion can lead to the formulation of and change in identity, rather than identity being rigid. Meanwhile, Read and Bartkowski (2000: 398), as well as Butler (2013a), observed how such discussion arises in discursive spaces, wherein daily physical and social activities' validation is possible via participants being furnished with the requisite resources and symbols. Mindful of this, analysis of PWS' lived experiences must encapsulate all aspects informing the individual's experience, as opposed to simply the experience of the individual 'who stutters', because the stuttering experience is an aspect of wider experience. Understanding stuttering experiences as linked to wider experiences can facilitate the establishment of a holistic perspective of participants' overarching lived experiences, as this research has sought to achieve.

#### 7.3: PWS' Concepts of Stuttering as Related to the SRMD

The participants' life stories generated data that clearly evidenced PWS' self-definition of the stuttering concept. The participants described their stutter through clarifying its implications for their lives, how it happened and potentially their relationship to it. This reflects the SRMD perspective, positing that impediments must be understood as 'a phenomenon of disadvantage as opposed to a form of oppression' (Reindal, 2008, p. 138). Previous experiences, social interactions and barriers were perceived as creating this concept of disadvantage (Reindal, 2008). This study's findings evidence how PWS' everyday social experiences since they started stuttering may increase their level of disadvantage compared with non-PWS. The majority of the participants' definitions concerned what they could not do due to their stutter, in addition to how they felt about that. For example, this may concern how stuttering leads them to experience speech and social difficulties alongside negative feelings regarding the stutter and themselves. Therefore, the participants' definitions of the stutter concerned stuttering's effects.

In the SRMD, impairment's effects are a fundamental aspect of impaired people's experiences (Reindal, 2008; Thomas, 2004). Accordingly, the stuttering's effects need to be a fundamental component of the stuttering definitions or concepts, in addition to the social and structural restrictions. This is because having a stutter distinguishes PWS from individuals who do not stutter in the first place. The participants in this study referred to this disadvantage of stuttering firstly on the basis of generating it from their comparison with non-PWS during numerous social interactions. For example, one participant remarked: "I ask myself why I could not speak like everyone else". Thus, the speech impediment plays a role in the experience, although it occurs in social contexts. Social interaction potentially stresses PWS' differences in a negative manner. When PWS' differences were emphasised, this can lead to exclusion (Guttormsen et al., 2015; Nang et al., 2018). This experience is affected by PWS' intrapersonal interactions (their thoughts) (O'Dwyer et al., 2018). Their thoughts and feelings regarding their stutter and their hopes of managing their stuttering may contribute towards moulding their stuttering perspective (Tichenor & Yaruss, 2018; Ezrati-Vinacour & Weinstein, 2011).

Consequently, PWS' feelings relating to their stutter might be deemed a significant component of stuttering's definition, because it can explain stuttering's emotional effects on PWS. On this basis, stuttering's definition should be linked to people's personal circumstances, including their social experiences and individual cognition.

The participants' definition or description of the stutter might have developed within the social context. This includes past events and others' attitudes (Reindal, 2008; Thomas, 2004). People's interactions can inform the formulation of meaning, which is also apparent from the participants' narratives concerning their stutter's causes. Regarding these causes, particular participants attributed their stuttering to previous challenging events and times during their lives, including problematic childhood experiences such as scary situations or social anxieties. Each participant who narrated such events recalled intimidating scenes and difficult stories, relating to either their personal recollections or what others had told them second-hand regarding their experiences, which they considered had potentially triggered their stutter. Therefore, it seems that PWS' prior experiences—irrespective of their personal recollection of them or others retelling of the experience to them—potentially play a role in PWS' reconstruction of concepts pertaining to their stuttering's causes. Therefore, if PWS acquired information from others regarding their stuttering's causes, specifically their parents (Safwat & Sheikhany, 2014), they might have accepted this explanation. For example, certain participants narrated stories from their childhood, deeming them as explaining their stuttering's cause. Some of these stories were recalled by their parents, with the participant subsequently adopting such narratives to explain their stutter's emergence.

Consequently, such narratives may occupy a fundamental position in their mind, providing a reason for why their stutter emerged. Indeed, participants' cognisance of what caused their stuttering was not anticipated in this research, because such comprehension remains vague (García-Pastor & Miller, 2019). This was reflected in the participants in this study, whereby they have internalised some erroneous information pertaining to their stuttering's cause based on interactions with parents and teachers. Significantly, the majority of parents and teachers remain misinformed about their stuttering's causes (Safwat & Sheikhany, 2014; Abdalla & St. Louis, 2012). Therefore, throughout these relationships and interaction with other individuals, participants might have been led to formulate their stuttering concept via intrapersonal-external communication. Ultimately,

the findings indicate that the participants' knowledge about the stutter were moulded by participants' experiences and social interactions.

Incorporating lived experience as an aspect of stuttering definitions' formulation reflects the SRMD, because any impediment's experience is a construct underpinned by the meaning that people derive from their interactions (Reindal, 2010). Furthermore, understanding the stuttering definition and concept as a lived experience accords with the updated International Classification of Functioning, Disability and Health (ICF) model (Yaruss & Quesal, 2004). The ICF refined this through classifying specific elements of the stutter behaviours and lived experience of PWS, alongside contemporary scientific understanding of stuttering's underlying nature. This permits in-depth understanding of stuttering as something existing within individuals' speech, thoughts and feelings (Ezrati-Vinacour & Weinstein, 2011). This data's significance lies in how it enables the understanding of stuttering as a subjective (individualised) meaning, which has been created via their social interactions (Blumer, 1969; Reindal, 2008). On another level, these findings are valuable for providing original insight into life aspects that are difficult to measure and quantify, as well as those which have not been sufficiently focused on by other researchers (O'Dwyer et al., 2018).

On this basis, this study's findings permit in-depth discussion of how one's conception of stuttering is a construct of one's lived experience. Subsequently, this knowledge may assist with perceiving the stutter in relation to human experiences, as opposed to objective circumstances. Conceptualising stuttering in this manner can facilitate understanding and fulfilment of PWS' requirements. In accordance with the SRMD, societal obstacles are typically confronted by PWS when attempting to access a sufficient level of support throughout their lives (Reindal, 2008). One barrier that must be considered here is how the academic definition of the stuttering concept does not sufficiently represent what stuttering means to the individuals. For PWS, stuttering is not solely a speech condition, because they also have a history and relationship to it which has affected them, as well as which they have dealt with. Therefore, PWS' own understanding of the stuttering concept may bridge this gap between the academic definitions and real experiences.

# 7.4: Reflection on The Use of The SRMD for Interpreting Participants' Narratives

Adopting the SRMD for interpreting participants' narratives has enabled the demonstration of how they formulate meaning from their intrapersonal-external interactions. Resultantly, the SRMD enabled PWS' voices to be heard. This is due to the SRMD being an expansive framework which encapsulates rather than overlooks the numerous elements that PWS may wish to discuss in relation to their experiences, thus subsequently increasing our awareness of their authentic and comprehensive experience.

In addition, elaborating on the interplay between the stutter, its effects and the negative consequence of the barriers affecting PWS, opens up ethical considerations and the potential for revealing unjust ideologies, practices and structures (Reindal, 2010). This is due to the SRMD respecting the role of individuals and societal restrictions' effect on shaping people's lived experiences. For example, the speech impediment can lead to individual barriers to PWS benefitting from the same life opportunities that people who do not stutter have, with socially imposed barriers (for example insufficient social and educational support) also having an effect. Similarly, cultural assumptions about stuttering and PWS may affect how PWS feel about themselves and their experience.

Nevertheless, despite the SRMD being an overarching model involving both the effect of impairments and social barriers, this provides greater weight to negative social influences' impairment of experience. However, this does not explain how a healthy and supportive society can have a positive effect on people's experiences. Accordingly, the research findings pertaining to PWS' positive experiences could not be directly interpreted based on the SRMD. Rather, the findings were interpreted through suggesting that if negative social interactions undermine people's experiences, then positive social interaction may eliminate social barriers and enhance people's experiences. Even so, adopting the SRMD generally provided sufficient room to cover all individual and social dynamics linked to one's experiences. Consequently, all of the research findings may be perceived through the lens of the SRMD. This is due to the participants conveying messages regarding their lived experiences that reflected their perceptions of their current lives as either affected or unaffected by their overall experience. Consequently,

participants' perceptions of their lived experiences could be deemed a construct of their thoughts relating to external influences throughout their lives, meaning these findings were in one way or another situated under the SRMD.

The discussion of the narrative type that participants adopted during their life stories' reconstruction concluded with certain recommendations for dealing with the stuttering's effects and social barriers, aiming to enhance their overall stuttering experience. However, it should be emphasised that these recommendations are not presented as a guaranteed approach for reducing the stutter, yet they might enhance certain PWS' abilities to cope with their stutter. Therefore, improvements to quality of life might be secured. As presented based on the participants' narrative type, it is apparent that the principal aspect determining their lives is themselves (self-imposed). The participants ranged from feeling they are continuing to endure difficulties because of being unable to forget their childhood, to participants who had managed to accept their stutter and who felt that it is not a problem for them. These differences may be linked to the manner in which they dealt with their experiences. The following summarises the recommendations and advice generated from the participants' life stories:

- It is particularly significant to listen to PWS' voices to comprehend the manner in which they view their experiences, as well as to understand how they evaluate their interactions with others. This can assist with supporting providers, for example parents and teachers, with understanding how their children and students prefer to be treated and supported.
- Self-acceptance appeared to be a highly significant variable that has enhanced participants' lived experiences;
- The ability to disclose and discuss the stuttering topic was perceived as enhancing self-acceptance and others' reactions;
- Linking stuttering experiences to faith may transfer their experiences to the spiritual level, providing a life approach to living with the stutter;
- Having a role model among historical figures or modern people can offer a degree of support for coping with negative consequences;
- Concentrating on PWS' age and context is required during the process of providing them with appropriate support. Older PWS who have successfully

- managed to pass through challenging life stages may be able to support younger PWS, through providing them with a vision of a brighter future ahead for them;
- Accepting that stuttering is simply one aspect of the self, rather than being an inclusive self, means that the speech impediment should not undermine or define the person's self.

To conclude this section, it is significant to emphasise that the aforementioned recommendations have contributed to shaping the experiences of some of the 16 Saudi Arabian PWS who participated in this study. In this regard, they may or may not assist other PWS with fulfilling their needs in various contexts or who are of different ages.

# **Chapter 8: Conclusion and Recommendations**

This concluding chapter presents an overview of the current study (Section 8.1), as well as describing this study's contribution to knowledge (Section 8.2). Section 8.3 provides the study implications and recommendations, for researchers and support providers. Section 8.4 presents personal reflection, while section 8.5 discusses the study limitations, with section 8.6 recommending areas for future research. Section 8.7 is the concluding remarks.

#### 8.1: Overview

This study aimed to investigate sixteen Saudi Arabian PWS's perceptions of their lived experiences, and to explore the type of narrative they adopt while reconstructing their life stories. The SRMD and Symbolic Interactionism were adopted for conceptualising those elements that shape PWS' expressions of their life stories with stuttering. Having conducted life story interviews and applied analytical methods, the findings evidence the role of intrapersonal-external interactions in shaping the participants' subjective overall experiences of stuttering. However, individuals have the principal role in such interactions. Individuals' life stories and their manner of discussing them permits an understanding of how, sometimes, the participants may personally shape their experiences to a greater extent than the societies they reside in or their interactions with those societies potentially do. Ultimately, the participants' intrapersonal interactions possibly have the greatest influence in shaping their personal experience.

Consequently, the stuttering experience could be considered as an output of PWS' cognition, regardless of their experiences possibly having been constructed on the basis of something that they experienced externally via their social interactions, with the stuttering experience ontology being constructed within PWS' minds. One example is how the ontology of feelings, emotions and memories in the life story derive principally from people's minds (Takeda et al., 2019). Accordingly, the stuttering experience creation process is possible to define as an intrapersonal interaction between ontology's two main perspectives, namely materialism and idealism. The matter pertains to the social effect (and potentially the stuttering condition), whereas the 'idea of the experience' and the manner of its construction resides in people's minds.

More specifically, the study results have illuminated dynamics with potential significance to Saudi Arabian audiences and those in other countries, particularly regarding the comprehension of how PWS may possess diverse perspectives in relation to their stuttering experiences. Moreover, these results could be implemented as a framework for providing practical and tangible recommendations for enhancing PWS' academic and professional experiences.

# 8.2: Contributions to Knowledge

This research makes four principal contributions to the research field of PWS' lived experiences, which are detailed below.

### 8.2.1: The Contribution of the Study Context and Participants

To the best of our knowledge, this study is one of the first qualitative research studies that has been conducted with Saudi Arabian PWS, with the aim of investigating their lived experiences. Therefore, the study has promoted further inquiry into the field of PWS' stuttering experiences and the interactional elements affecting their experiences, specifically in Saudi Arabia, where this type of research is limited (Alquraini, 2010). Despite the research sample potentially being insufficiently representative of Saudi Arabia's entire PWS population, it nonetheless can offer valuable revelations regarding particular PWS' lived reality. Additionally, the study's inclusion of eight females who stutter will assist with addressing a gap in the research, where limited research has been conducted that includes or focuses on woman who stutter (Nang, Hersh, Milton & Lau, 2018).

Moreover, the majority of participants indicated that they were not given the opportunity to access treatment from speech pathologists. This itself may contribute to filling the gap pointed out by Connery et al. (2019), namely that the majority of previous research participants' lived experiences of stuttering had involved some manner of treatment. Accordingly, this research provides data regarding the lived experience of adults PWS who have not received external support. Finally, all of the participants voluntarily provided their stories without being asked in person, resulting in the participants being

comprised solely of individuals who wanted to provide their life story. This helped to ensure effective and ethical research practice.

#### 8.2.2: The Contribution of the Data Collection Method

The data collection methods adopted for this study are a contribution to research in this field, given that they were conducted online, thus facilitating the process of listening to PWS' voices. The participants contributed their life stories in a complete form online via Snap Chap or email, without using the traditional method of face-to-face interviews. In this regard, this study provides a case of successful collection of data of sufficient length and quality from research participants who wrote and/or orally recorded their own voices, with limited interruptions.

Furthermore, adoption of the life story method accompanied by visual materials makes a positive contribution to the stuttering research field, because there has been a tendency to implement other qualitative research methods, for instance semi-structured interviews and focus groups (Isaacs & Swartz, 2020b). The adoption of this collection method has assisted with attaining this study's aim of listening to PWS, thus empowering them through the research. For some PWS oral interviews may particularly result in stress, so they can participate by writing their stories and still make their voices heard. The life story method has provided a space for the participants to freely structure their experience, through which the participants could narrate various aspects of their experience. The participants' life stories offered an array of personal data highlighting how each PWS perceives their experiences.

# **8.2.3:** The Contribution Made by this Study's Theoretical Framework in Terms of Reducing Negative Stereotyping

The use of the SRMD in this study has contributed to the research field of PWS' lived experience of stuttering, providing an example and illustration of how such experiences may be studied via a specific theoretical research framework. Adopting the SRMD as a framework for understanding the stuttering experience could promote a worldwide change in the public perception of PWS. This is due to the SRMD being able to support

people's perception of stuttering not as a disorder but rather a 'necessary condition', that may or may not result in limiting PWS' experiences, depending on the internal and external elements (Reindal, 2008). Therefore, adopting the SRMD can help to mitigate negative stereotyping due to PWS not being perceived as 'less able' compared with non-PWS, although they may confront external barriers that can affect their lives. Subsequently, this can point to the need to eliminate external barriers. For example, in the educational system, students who stutter should be provided with educational opportunities just like students who do not stutter, by introducing some adjustments to teaching and assessment strategies. Respecting personal experiences of stuttering in addition to the barriers that each individual confronts can result in their reduced presence in school or social contexts, thus providing a tangible advantage in terms of supporting PWS.

The SRMD approach may be applied broadly, given that the SRMD is a wider framework that is able to appraise varied personal, social and cultural elements; these subsequently underpin the development of a comprehensive picture of an individual's stuttering experience. Ultimately, the SRMD's adoption while exploring the lived experience of stuttering can contribute to our understanding regarding PWS' lived experiences, reducing the negative beliefs attached to such experiences. This may potentially enhance public opinion towards PWS and their abilities. This can be an essential remedy of the tendency towards negatively stereotyping PWS during research studies; this will be discussed further in section 8.3.5.

### 8.2.4: The Contribution of the Research Findings

This study's findings have contributed to the research field of lived experiences of stuttering, through providing subjective data and personal meanings that were perceived as diverging from the way in which such experiences have been explored and discussed in the extant research. This involved recommendation for support in accordance with the participants' voices. This point will be discussed in greater depth in the subsequent section.

# 8.3: Study Implications and Recommendations

This section discusses the potential implications and recommendations from the study results for academics in the stuttering field, in addition to those who provide support to PWS.

# **8.3.1: Stuttering Concept**

The first implication concerns the stuttering concept as described by the participants. The conception of stuttering among participants differed from how it has been defined in the literature. Preferably, this study adopts the term 'concept' in reference to how participants described their stutter, whereas descriptions in the literature were referred to as 'definition'. Stuttering was a concept for the participants due to it being an aspect of their lives and indeed themselves. Therefore, it may be assumed that the participants had thought about the stuttering concept prior to their involvement in this study; it may have already been constructed from the time they recognised their stutter. Accordingly, the conceptualisation of their stutter pertains to their feelings, thoughts and interpretations of how stuttering affects their lives, as well as why and how it happened. All of this may be reconstructed via the stories and events that they have experienced and dealt with.

Contrastingly, academic research typically attempts to define stuttering for educational purposes, tending to describe it according to its clinical aspects although not as an aspect of a person's experience. This study suggests that stuttering should always be perceived as a concept within individuals, due to their stutter being changeable (Nang et al., 2018), with each individual having a distinctive conception of stuttering. On this basis, the stuttering concept to a greater extent concerns what stuttering means for the person, rather than what the condition and symptoms are. Thus, based on this study's sample, it may be stated that a gap exists between researchers' findings about stuttering and what PWS say.

# 8.3.2: Perceived Type of Support

The second implication concerns raising awareness about supporting PWS. The findings suggest that *how* PWS were provided with support was more significant than *how much* support was available to them. This study has investigated what participants perceived as being appropriate or inappropriate support. The results suggested that some support

received by participants from their parents and teachers did not fulfil their requirements. Resulting in a discordance between the support that other people provided to the participants and what the participants actually wanted. Alongside the dearth of literature involving PWS' voices with regards to the support they want, this can also result in the strategies adopted for supporting PWS not being focused on key aspects identified by the PWS themselves that can have the biggest effect in terms of support. Therefore, this study suggests that accurately reflecting PWS' preferred support could yield improved support strategies for the individuals. Ultimately then, it is recommended that PWS' voices are listened to when considering how best they can be supported and their experiences enhanced.

This study's findings also offer some suggestions for support providers, particularly families, teachers and speech therapists, who have a likelihood of having a degree of influence on PWS' experiences. As presented in the research findings, a significant aspect of the participants' life stories involved memories of events wherein the role of parents and teachers were presented; this can mean there was a long-lasting effect of those people on the participants' experience. Consequently, increasing the awareness of parents, teachers and even speech therapists may enhance their abilities to meet PWS' needs when they require support due to enduring a difficult experience.

### 8.3.3: PWS' Positive Achievements Enhanced their Lived Experience

The results have evidenced the role of positive events and stories in producing affirmative perceptions of their overall lived experience. Positive events pertain to the participants' life attainments, for example strong school performance, successfully completing an oral presentation, or receiving positive feedback from teachers or parents. Such positive experiences were considered to be highly encouraging for participants' development of their self-acceptance and reduction of avoidance behaviours. Contrastingly, negative past experiences, for example being unable to produce an answer, negative feedback and bullying, could contribute towards shaping their perception of a negative overall experience. Consequently, this study suggests that PWS must be involved in more opportunities for positive experiences and achievements, through concentrating on their strengths. Simultaneously, other stressful situations need to be reduced, for example

asking students to introduce themselves, which was considered by participants to be their most difficult school experience. This will enable their educational and social experiences to be enhanced.

#### 8.3.4: PWS' Attitudes towards their Societies

This study's findings have considered the role that PWS' holding positive attitudes towards their society has had in their overall experience. It is recommended that PWS should be involved in all research touching on their experiences. This should bring into question the type of research focusing on public attitudes that has typically been undertaken as a means of measuring non-PWS' attitudes towards PWS, yet which has not involved PWS themselves.

Research has suggested that there is a need to improve public attitudes toward stuttering and PWS (Wesierska & Przepiorka, 2019). Nevertheless, research investigating public attitudes regarding PWS has overwhelmingly not involved PWS. Thus, in terms of how researchers determined what accounts for a positive or a negative attitude, this should be based on PWS' actual perceptions. We can connect one of the findings about parental attitudes with other studies that have measured parental attitudes, as a means of appraising how they can mutually support each other. One example concerns how parents in research elsewhere stated that they feel a degree of self-blame, because they were unaware of how they could support their children who stutter (Langevin et al., 2010). Such parental concerns could be resolved by some of the insights from the participants in this study. Those participants remarked that the support they required from their parents was to help them avoid being negatively affected by their stutter and to accept them as they are. This is just a single example of the role that PWS play personally in improving the knowledge of others.

Moreover, engaging PWS in research seeking to measure public attitudes may be undertaken by turning the focus around, asking PWS about their attitudes towards their society as opposed to measuring public attitudes towards PWS. To clarify, this does not involve asking PWS about their social experiences, nor how they perceive others' attitudes. Rather, the aim should be to investigate whether PWS hold positive attitudes towards others. This idea was generated from the study results, namely certain

participants' expression of the ability to accept other individuals' differences, for example the lack of education or others' psychological problems. The study results indicated that when the participants (PWS) built positive attitudes towards the people in their surroundings (non-PWS), they strengthened their self-acceptance and quality of life. Therefore, this study advocates that research is conducted into PWS' attitudes towards society, while also promoting PWS' attitudinal improvement towards their societies and their acceptance of one another.

A further moral advantage of enabling PWS to speak out about their attitudes towards society is that it shifts the focus away from non-PWS who may already be empowered in their societies, thus giving greater value to PWS' attitudes and opinions. In this regard, given that the majority of research studies assess public attitudes regarding stuttering and PWS, it may be worthwhile to research the degree to which PWS may possess positive attitudes towards their societies. Specifically, how PWS can understand that their societies may involve people who are unstable, for instance people who want to bully and hurt others due to their own difficult lives or psychological problems, is significant. Greater research into PWS' understanding of their societies may improve the manner in which PWS view their experiences, for example, they may feel that their stuttering experiences are not as bad as those afflicting other people in their societies, even those individuals who react negatively to PWS through bullying and teasing. Ultimately then, there is a general need for greater self-acceptance. This might aid PWS with mitigating the potential detrimental outcomes of their social interactions, subsequently strengthening their quality of life.

Therefore, this study recommends that PWS and support providers can aim to develop PWS' willingness to deal with all manner of people in their societies. This study argues that PWS' response, reflection and meaning making in relation to their surroundings, can mitigate the effect of negative social interactions through which limited acceptance, social stigma and related problems are possibly invited. On this basis, participants' individual characteristics may determine the extent to which they can effectively deal with social challenges, while residing within a supportive and encouraging environment can facilitate the eradication of social barriers, ultimately leading to PWS' enhanced experiences.

## 8.3.5: The Stereotyping of PWS in Research Studies

This implication pertains to stereotyping in research into PWS' lived experience of stuttering. The literature evidence, as well as that from the data collected through this study, supports the argument that negative stereotyping of PWS' experiences must be reduced. This in order to reduce the potential negative implications on other people, for instance parents, teachers and employers, which may negatively reflect on PWS. Consequently, this study's research process has provided an updated or enhanced approach for analysing PWS' lived experiences, which could be applied during further research involving other individuals who may be considered vulnerable. This updated approach is arguably more moral and respectable, while also empowering those individuals being researched. This approach is based specifically on the modification of methods and researchers' expectations regarding others' experiences. The SRMD's use facilitated this approach by providing a balanced and unbiased conceptual framework for interpreting PWS' experiences. The SRMD provides a forward-thinking approach to understanding the lived experience of stuttering, although few researchers have incorporated SRMD concepts in their studies. Applying the SRMD during research may hold positive implications for understanding PWS' lived experiences of stuttering and providing them with the necessary support.

Therefore, researchers investigating other people's lived experiences may proceed with this on the basis that they are expecting them to have experience that differ from others. This expectation of the experience has a greater likelihood of being negative and diverging from the 'norm', as for example in Klompas and Ross (2004) as well as Beilby et al.'s (2013) research. This is not to say that these experts have not proceeded correctly, indeed, PWS' difficult experience must be investigated and listened to. Regardless, such an emphasis can result in negative stereotyping, particularly with PWS possibly being subjected to negative stereotyping around them having social, academic and professional difficulties (Boyle, 2013; Bricker-Katz et al., 2013; Boyle et al., 2016).

In this regard, there is a requirement to concentrate on the role of personality, which can determine whether PWS are ultimately affected or unaffected by their stutter. Respecting PWS' subjective role in shaping their experiences may result in appreciation of PWS'

efforts to mainline positive experiences, as well as support those with negative experiences. Arguing for PWS' positive experiences does not directly equate to them having had supportive social and cultural environments, although this can be referred to as part of the person's character. One example is how certain participants worked on developing their personalities as a means of enhancing their quality of life. Respecting PWS' subjective role may support those whose experience was negative, by indicating some changes they could implement at the personal level, with regards to the way they perceive and deal with their experience. It should be observed here that the role of external elements, for instance home, school and society, has been considered in this study, although as elements 'ontologically' located within the person's mind in accordance with the SRMD.

Furthermore, the people who are the subject of research may wish to express the positive aspects of their stuttering experience, which should be similarly stressed. Although this study covered particular difficulties, for example, childhood difficult experiences, these comprise one aspect of their experience as opposed to their entire experience. Accordingly, this research has argued that adult PWS' lived experiences need to be investigated as a holistic process, rather than being focused solely on their difficulties, unless the purpose is to provide solutions. This could involve emphasising PWS' strengths rather than just their difficulties, as well as pointing out the 'normality' or similarities they share with all humans, instead of concentrating on the speech impediments, all of which can facilitate the development of positive attitudes towards PWS. Through doing so, the awareness of other people can be increased—including parents, teachers and employers—about what PWS can do as opposed to what they cannot do as a consequence of their speech impediment. This reflects the perspective of the participants in this study who emphasised that they have the ability to do everything. Nevertheless, this differs from researchers' perceptions, who have spent decades focusing on stuttering's negative effects, which subsequently could exacerbate PWS' social marginalisation while also emphasising their vulnerability.

This research has aimed to diminish the negative stereotyping of PWS through presenting the participants' holistic experiences, which have involved positive aspects and development. Subsequently, this could prove significant with regards to permitting PWS to expound upon their stuttering experiences without overlooking further significant dynamics which could be connected to their experiences, yet which are indirectly linked to their stutter. The manner in which the PWS appraised their previous and present experiences, alongside the effects of these experiences on their lives, conveys their individual perspectives concerning the interpersonal-external interactions they have engaged in throughout their lives. This permits a degree of investigation into how events experienced by the participants have potentially informed the cognitive processes via which they linked these experiences to their overall life stories. Therefore, participants' stories pertaining to events they have experienced are inevitably connected to their entire life stories; even when two participants have experienced similar events, they will evaluate these from differing perspectives, consequently generating diverse experiences for the individuals involved. The reason for this is that having contacted participants and engaged with them, it was apparent that PWS may not necessarily appreciate being perceived as disadvantaged individuals.

### 8.4: Personal Reflection

My personal rationale for undertaking this research was increasingly bolstered upon receiving the various participants' life stories. This research was conducted in accordance with my personal perspective of stuttering, which emphasises that stuttering is not a fixed condition but rather reflective of an individual's experience. Consequently, respecting PWS' differences was particularly significant for comprehending that PWS can have varying perceptions of their personal experience of stuttering, while not all of the participants perceived stuttering to have affected their lives. In this basis, I discovered that as a researcher I have the capability to limit bias, while aiming to listen and understand participants' perspectives which sometimes differed markedly from my own. Prior to the data collection process, I was influenced by my in-depth engagement with the stuttering field literature, seeking to understand PWS' lived experiences, alongside the investigation of certain social and cultural effects on PWS, for example the social anxieties and prejudices they potentially encounter. However, via the contact with the research participants, my knowledge has been enriched further regarding PWS' experiences, with their lived experiences evidently not being entirely concerned with the challenges stemming from their stutter or social obstacles. Subsequently, this transformed my rationale from being simply an analysis of PWS' educational, social and cultural experiences, to seeking to challenge the negative stereotyping of PWS, with emphasis being placed on the significance of listening to PWS personally describe their stuttering experiences.

Additionally, I have observed another change in my position; prior to the participants' recruitment, I was uncertain whether PWS would be motivated to participate. Nevertheless, participants expressed willingness to participate simply with the aim of enhancing public awareness of their experiences, while also attempting to transform negative stereotyping. I have attributed this to the participants superior insight into their challenges, further emphasising the significance of me as the researcher perceiving my role as being effectively listening to participants' voices and perspectives. Consequently, my rationale involved the moral aim of honestly presenting participants' experiences in a manner that captures the diverse meanings they assign to such experiences.

Simultaneously, listening to PWS' difficult experiences affected me emotionally; when they told me about overcoming their difficulties, I felt better. Contrastingly, when other participants appeared to still be struggling due to their past experiences, I felt helpless. Indeed, I was unable to stop thinking about their situation, how a person could still be unhappy due to experiences during their childhood. Although I was emotionally affected by the participants' life stories, I was pleased about this, given that it inspired me to undertake further research into potentially effective interventions. My future research intervention will not just be focused on reducing PWS' stutter, it will also aim to identify ways to enhance PWS' quality of life. With the participants indicating to me how enhancing their quality of life and acceptance was their personal choice, it is apparent that adopting methods to support PWS' development of self-acceptance could potentially improve their lives.

## 8.5: Limitations of the Study

One potential research limitation is the dearth of older PWS who participated in this study, which was potentially due to using the internet and social media to reach possible participants; this may not have attracted a sufficiently wide range of ages, or it is perhaps

that older PWS felt less motivated to participate. One approach to resolving this issue in future research would be to encourage older PWS to participate through explaining the value that their knowledge and experience has in terms of supporting younger PWS.

Nevertheless, because this research has not aimed to generalise the findings, the sample of 16 participants aged between 18 and 57 could be deemed as being of a sufficient size to enable the drawing of meaningful conclusions. Furthermore, this study only involved participants from Saudi Arabia, meaning the findings may or may not be applicable to other individuals in different contexts. Another aspect may not be considered a limitation although it is worth mentioning, namely that online interviewing was not as beneficial as face-to-face interviewing for coming to know the participants in person. Even so, it did provide PWS with greater privacy, which could have encouraged the participants to provide me with life stories of considerable duration and that are highly personal.

### 8.6: Future Research

Based on this research findings and the related discussion, it could prove highly beneficial for future research into lived experiences of stuttering to involve PWS and other people surrounding them, as a means of presenting how their attitudes differ. As presented in the research findings, the participants had differing perceptions of the forms of assistance provided by their families and teachers, meaning that engaging PWS and some of the people who interact with them could enable a line to be identified between what support the PWS' need and the support they actually perceive. This could be achieved through applying the focus group method. In future research, there could be more emphasis on exploring solutions for enhancing the experience of stuttering, for instance analysing the effectiveness of discourse and reducing the severity of stuttering.

Additionally, if I had sufficient time, I would have asked the participants in this study whether their participation in this research, as well as the reflection holistically on their entire life that it involves, has helped them to perceive their lives differently in any way. For example, has it influenced the way they perceive themselves, as well as whether they

think participating in this study has shaped their life stories if they wanted to retell it at some point.

## 8.7: Concluding Remarks

Stuttering is an enduring speech impediment with far reaching effects. Conducting this research enabled core findings to be identified pertaining to the efforts that the participants had to make during their lives, in order to deal with the adverse implications of stuttering, social as well as structural barriers, particularly relating to their educational and employment opportunities. However, regardless of them engaging in greater exertion compared with non-PWS, PWS may have fewer life opportunities than non-PWS. This is due to social barriers, for example negative social stereotyping, as well as structural barriers, for example educational sectors necessitating oral skills as a means of testing students' performance. Such everyday life difficulties that participants experienced contributed to their identity formation, thus what they believe they can and cannot do. Certain participants attempted to prove their abilities through attaining good educational and professional performance, although avoidance behaviours were the principal barrier that prevented participants from expressing their educational and professional knowledge. This barrier was self-imposed in order to avert stressful situations, as well as socially-imposed due to others' insufficient awareness and negative reactions.

Consequently, all people interested in enhancing the stuttering experience should aim to remove these social and structural barriers by, for example, raising awareness and adjusting the schooling strategies for students who stutter. Simultaneously, PWS should be supported to manage and overcome potential social and educational obstacles, for instance through encouraging PWS to discuss their stutter with teachers and friends, explaining how they want to be supported, as opposed to hiding their stutter. This study emphasises the significance of listening to PWS' voices; it may be stated that the major aim of effectively hearing participants' voices through the research has been attained. Their voices have contributed to knowledge through informing recommendations that could enhance PWS' experiences, alongside the strengthening of research approaches for analysing PWS' lived experiences.

## **References List**

- Abberley, P. (1987). The concept of oppression and the development of a social theory of disability. *Disability, handicap & society*, 2(1), 5-19.
- Abdalla, F. A., & St. Louis, K. O. (2012). Arab school teachers' knowledge, beliefs and reactions regarding stuttering. *Journal of Fluency Disorders*, *37*(1), 54–69. https://doi.org/10.1016/j.jfludis.2011.11.007
- Abdalla, F., & St. Louis, K. O. (2014). Modifying Attitudes of ArabAbdalla, F., & St. Louis, K. O. (2014). Modifying Attitudes of Arab School Teachers Toward Stuttering. Language, Speech, and Hearing Services in Schools, 45(1), 14–25. https://doi.org/10.1044/2013\_lshss-13-0012 School Teachers T. *Language, Speech, and Hearing Services in Schools*, 45(1), 14–25. https://doi.org/10.1044/2013\_lshss-13-0012
- Abrahams, K., Harty, M., St. Louis, K. O., Thabane, L., & Kathard, H. (2016). Primary school teachers' opinions and attitudes towards stuttering in two South African urban education districts. *South African Journal of Communication Disorders*, 63(1), 1–10. https://doi.org/10.4102/sajcd.v63i1.157
- Acton, C., & Hird, M. J. (2004). Toward a sociology of stammering. *Sociology*, *38*(3), 495–513. https://doi.org/10.1177/0038038504043215
- Adriaensens, S., Beyers, W., & Struyf, E. (2015). Impact of stuttering severity on adolescents' domain-specific and general self-esteem through cognitive and emotional mediating processes. *Journal of Communication Disorders*, *58*, 43–57. https://doi.org/10.1016/j.jcomdis.2015.10.003
- Adriansen, H. K. (2012). Timeline interviews: A tool for conducting life history research Hanne Kirstine Adriansen. *Qualitative Studies*, *3*(1), 40–55.
- Ahn, J., 2013, The study on elementary school teachers' recognition toward stuttering students in inclusive environment. Journal of Special Children Education, 15, 315–333.
- Al-Ahmadi, N. A. (2009). *Teachers' perspectives and attitudes towards integrating students with learning disabilities in regular Saudi public schools* (Doctoral dissertation, Ohio University).
- Albarracin, D., Johnson, B. T., & Zanna, M. P. (2014). *The handbook of attitudes*. New York, NY: Psychology Press. Retrieved from https://www.taylorfrancis.com/books/9781135626174
- Al-Gain, S. I., & Al-Abdulwahab, S. S. (2002). Issues and obstacles in disability research in Saudi Arabia. *Asia Pacific Disability Rehabilitation Journal*, 13(1), 45-49.
- Alghunaim, M., Abdullah, A., Alshaibi, S., Alfehaid, O., Albagami, M., Omair, A., & Anjum, I. (2020). Do males who stutter also experience excessive worry: a case-control study conducted in Saudi Arabia comparing worry among Saudi male stutterers with non-stutterers. *International Journal of Medicine in Developing Countries*, *March*, 645–651. https://doi.org/10.24911/ijmdc.51-1575308714
- Al-Kabbaa, A. F., Ahmad, H. H., Saeed, A. A., Abdalla, A. M., & Mustafa, A. A.

- (2012). Perception of the learning environment by students in a new medical school in Saudi Arabia: Areas of concern. *Journal of Taibah University Medical Sciences*, 7(2), 69-75.
- Al-Khaledi, M., Lincoln, M., McCabe, P., Packman, A., & Alshatti, T. (2009). The attitudes, knowledge and beliefs of Arab parents in Kuwait about stuttering. *Journal of Fluency Disorders*, *34*(1), 44–59. https://doi.org/10.1016/j.jfludis.2009.02.003
- Alm, P. A. (2004). Stuttering, emotions, and heart rate during anticipatory anxiety: A critical review. *Journal of Fluency Disorders*, 29(2), 123–133. https://doi.org/10.1016/j.jfludis.2004.02.001
- Alqhazo, M., Blomgren, M., Roy, N., & Abu Awwad, M. (2017). Discrimination and internalised feelings experienced by people who stutter in Jordan. *International Journal of Speech-Language Pathology*, *19*(5), 519–528. https://doi.org/10.1080/17549507.2016.1209561
- Alquraini, T. (2011). SPECIAL EDUCATION IN SAUDI ARABIA: CHALLENGES, PERSPECTIVES, FUTURE POSSIBILITIES. *Phys. Rev. E*, 26(2), 159.
- Al-Shdifat, K. G., Maayah, M., Mayo, R., & Louis, K. St. (2018). Attitudes of Communication Sciences and Disorders Students at Jordan University of Science and Technology toward Stuttering and People Who Stutter. *Communication Sciences & Disorders*, 23(4), 1005–1016. https://doi.org/10.12963/csd.18532
- Alshdifat, K., Mayo, R., & St. Louis, K. (2013). Attitudes of Jordanians toward stuttering and people who stutter. Paper presented at the Annual Convention of the American Speech-Language-Hearing Association, Chicago, IL.
- AlSheddi, M., Russell, S., & Hegarty, P. (2020). How does culture shape our moral identity? Moral foundations in Saudi Arabia and Britain. *European Journal of Social Psychology*, *50*(1), 97–110. https://doi.org/10.1002/ejsp.2619
- Al-Solaim, L., & Loewenthal, K. M. (2011). Religion and obsessive-compulsive disorder (OCD) among young Muslim women in Saudi Arabia. *Mental Health, Religion and Culture*, *14*(2), 169–182. <a href="https://doi.org/10.1080/13674676.2010.544868">https://doi.org/10.1080/13674676.2010.544868</a>
- Alvesson, M., & Sköldberg, K. (2009). Reflexive methodology: New vistas for qualitative research. Los Angeles: Sage.
- Alwhaibi, R. M., Zaidi, U., Alzeiby, I., & Alhusaini, A. (2020). Quality of Life and Socioeconomic Status: A Comparative Study among Mothers of Children with and without Disabilities in Saudi Arabia. *Child Care in Practice*, *26*(1), 62–80. https://doi.org/10.1080/13575279.2018.1512951
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (*DSM-5*®). Washington, DC: American Psychiatric Pub. Retrieved from <a href="https://ci.nii.ac.jp/naid/10010095609/">https://ci.nii.ac.jp/naid/10010095609/</a>
- Arnold, H. S., Conture, E. G., Key, A. P. F., & Walden, T. (2011). Emotional reactivity, regulation and childhood stuttering: A behavioral and electrophysiological study. *Journal of Communication Disorders*, *44*(3), 276–293. https://doi.org/10.1016/j.jcomdis.2010.12.003

- Asselin, M. E. (2003). Insider research: Issues to consider when doing qualitative research in your own setting. Journal for Nurses in Staff Development, 19(2), 99-103.
- Atkinson, R. (1998). The life story interview. Thousand Oaks, Calif.; London: Sage.
- Bagnoli A (2009) Beyond the standard interview: the use of graphic elicitation and arts-based methods. Qualitative Research 9(5): 547–570.
- Bailey, K (2004) 'Learning more from the Social Model: Linking Experience, Participation and Knowledge Production', In C. Barnes and G. Mercer (eds) Implementing the Social Model of Disability: Theory and Research. The Disability Press, Leeds. Available on the Disability Archivewww.leeds.ac.uk/disability-studies/archiveuk/
- Bailey, K., Harris, S. J., & Simpson, S. (2015). Stammering and the Social Model of Disability: Challenge and Opportunity. *Procedia Social and Behavioral Sciences*, 193, 13–24. https://doi.org/10.1016/j.sbspro.2015.03.240
- Ball, S., & Goodson, I. (2005). *Qualitative Research in Education: Focus and Methods* (R. R.Sherman & R. B.Webb (Eds.)).
- Bandura, A. (1989). Human agency in social cognitive theory. *American Psychologist*, 44(9), 1175.
- Barker, M. & Ritchie, A. (2005). Hot bi babes and feminist families: Polyamorous women speak out. Psychology of Women Section Review.
- Barnes, C., Oliver, M., & L. Barton (Eds) (2002) Disability Studies Today. Cambridge: Polity Press.
- Bar-On, D. (2006). Tell your life story: Creating dialogue among Jews, Germans, Israelis and Palestinians. Central European University Press, Budapest
- Beilby, J. M., Byrnes, M. L., Meagher, E. L., & Yaruss, J. S. (2013). The impact of stuttering on adults who stutter and their partners. *Journal of Fluency Disorders*, 38(1), 14–29. https://doi.org/10.1016/j.jfludis.2012.12.001
- Belyk, M., Kraft, S. J., & Brown, S. (2015). Stuttering as a trait or state –An ALE metaanalysis of neuroimaging studies. European Journal of Neuroscience, 41(2), 275– 284
- Berends, L. (2011). Embracing the visual: Using timelines with in-depth interviews on substance use and treatment. *Qualitative Report*, 16(1), 1-9.
- Bhatia, S., & Ram, A. (2001). Acculturation, dialogical voices and the construction of the diasporic self. Commentary: Culture and Psychology, 7, 297-309.
- Biggs, H. C., & Hinton-Bayre, A. D. (2008). Telling Tales to End Wails: Narrative Therapy Techniques and Rehabilitation Counselling. *The Australian Journal of Rehabilitation Counselling*, *14*(1), 16–25. https://doi.org/10.1375/jrc.14.1.16
- Blood, G. W., & Blood, I. M. (2004). Bullying in adolescents who stutter: Communicative competence and self-esteem. Contemporary Issues in Communication Science and Disorders, 31,69–79

- Blood, G. W., & Blood, I. M. (2016). Long-term Consequences of Childhood Bullying in Adults who Stutter: Social Anxiety, Fear of Negative Evaluation, Self-esteem, and Satisfaction with Life. *Journal of Fluency Disorders*, 50, 72–84. https://doi.org/10.1016/j.jfludis.2016.10.002
- Blood, G. W., Blood, I. M., Tellis, G., & Gabel, R. (2001). Communication apprehension and self-perceived communication competence in adolescents who stutter. *Journal of Fluency Disorders*, 26(3), 161-178.
- Blood, G. W., I. M. Blood, G. M. Tellis, and R. M. Gabel. (2003). "A Preliminary Study of Self-Esteem, Stigma, and Self-Disclosure in Adolescents Who Stutter." Journal of Fluency Disorders 28 (2): 143–159. doi:10.1016/S0094-730X(03)00010-X.
- Bloodstein, O. (1995). A handbook on stuttering (5th ed.). San Diego, California: Singular.
- Blumer, H. (1969). Symbolic Interactionism: Perspective and Method. London: University of California Press.
- Blumgart, E., Tran, Y., & Craig, A. (2010). An investigation into the personal financial costs associated with stuttering. *Journal of Fluency Disorders*, 35(3), 203-215.
- Bodur, S., Torun, Y. T., Gül, H., Dincer, M., Gül, A., Kara, K., Karaman, D., Durukan, I., & Cöngöloglu, M. A. (2019). Parental attitudes in children with persistent developmental stuttering: A case-control study. *Revista de Psiquiatria Clinica*, 46(4), 103–106. https://doi.org/10.1590/0101-60830000000204
- Booth, T. & Booth, W. (2005) Parents with learning difficulties in the child protection system, Journal of Intellectual Disabilities, 9(2), 109–129.
- Bothe, A. K., Davidow, J. H., Bramlett, R. E., Franic, D. M., & Ingham, R. J. (2006). Stuttering treatment research 1970–2005: II. Systematic review incorporating trial quality assessment of pharmacological approaches. *American Journal of Speech-Language Pathology*, *15*, 342-352.
- Bowers, A., Saltuklaroglu, T., & Kalinowski, J. (2012). Autonomic arousal in adults who stutter prior to various reading tasks intended to elicit changes in stuttering frequency. *International Journal of Psychophysiology*, 83(1), 45–55.
- Boyle, M. P. (2013). Assessment of Stigma Associated With Stuttering: Development and Evaluation of the Self-Stigma of Stuttering Scale (4S). *Journal of Speech, Language, and Hearing Research*, *56*(5), 1517–1529. https://doi.org/10.1044/1092-4388(2013/12-0280)
- Boyle, M. P. (2015). Relationships between psychosocial factors and quality of life for adults who stutter. *American Journal of Speech-Language Pathology*, 24, 1–12.
- Boyle, M. P., Beita-Ell, C., Milewski, K. M., & Fearon, A. N. (2018). Self-Esteem, Self-Efficacy, and Social Support as Predictors of Communicative Participation in Adults Who Stutter. *Journal of Speech, Language, and Hearing Research*, *61*(8), 1893–1906. https://doi.org/10.1044/2018 jslhr-s-17-0443

- Boyle, M. P., Daniels, D. E., Hughes, C. D., & Buhr, A. P. (2016). *Considering Disability Culture for Culturally Competent Interactions With Individuals Who Stutter*. 43, 11–22.
- 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
- Boylea, M. P. (2017). Personal Perceptions and Perceived Public Opinion About Stuttering in the United States: Implications for Anti-Stigma Campaigns. *American Journal of Speech-LM.P.*, B. (2017). Personal Perceptions and Perceived Public Opinion About Stuttering in the United States: Implications for Anti-Stigma Campaigns. American Journal of Speech-Language Pathology, 26(3), 921–938. https://Doi.Org/10, 26(3), 921–938. https://doi.org/10.1044/2017\_AJSLP-16-0191 LK
  - http://findit.library.jhu.edu/resolve?sid=EMBASE&issn=15589110&id=doi:10.104 4%2F2017\_AJSLP-16-
  - 0191&atitle=Personal+Perceptions+and+Perceived+Public+Opinion+About+Stutt ering+in+the+United+States%3A+Implications+for+Anti-
  - Stigma+Campaigns&stitle=Am+J+Speech+Lang+Pathol&title=American+journal +of+speech-
  - language+pathology&volume=26&issue=3&spage=921&epage=938&aulast=Boyl e&aufirst=Michael+P.&auinit=M.P.&aufull=Boyle+M.P.&coden=&isbn=&pages =921-938&date=2017&auinit1=M&a
- Brady, A. (2006). Opportunity sampling. *The SAGE dictionary of social research methods*, 205-6.
- Branfield, F. (1998). What are you doing here?'Non-disabled'people and the disability movement: A response to Robert F. Drake.
- Brannen, J. (2004). Working Qualitatively and Quantitatively. *Qualitative Research Practice*, 1, 282–296. https://doi.org/10.4135/9781848608191.d25
- Brannen, J. (2013). Life story talk: Some reflections on narrative in qualitative interviews. *Sociological Research Online*, *18*(2), 48-58.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101.
- Bricker-Katz, G., Lincoln, M., & Cumming, S. (2013). Stuttering and work life: An interpretative phenomenological analysis. *Journal of Fluency Disorders*, *38*(4), 342–355. https://doi.org/10.1016/j.jfludis.2013.08.001
- Bricker-Katz, G., Lincoln, M., & McCabe, P. (2009). A life-time of stuttering: How emotional reactions to stuttering impact activities and participation in older people. *Disability and Rehabilitation*, *31*(21), 1742–1752. https://doi.org/10.1080/09638280902738672
- Bricker-Katz, G., Lincoln, M., & McCabe, P. (2010). Older people who stutter: Barriers to communication and perceptions of treatment need. *International Journal of Language and Communication Disorders*, 45(1), 15–30. https://doi.org/10.3109/13682820802627314

- Brinkmann, S. & Kvale, S. (2005) Confronting the Ethics of Qualitative Research. Journal of Constructive Psychology, 18, (2), 157-181.
- British Educational Research Association [BERA] (2018) Ethical Guidelines for Educational Research, fourth edition, London. https://www.bera.ac.uk/researchers-resources/publications/ethical-guidelines-for-educational-research-2018
- Bruner, J. S. (1986). Actual minds, possible selves. Cambridge, MA7 Harvard University Press.
- Butler, C. (2013a). Identity and stammering: Negotiating hesitation, side-stepping repetition, and sometimes avoiding deviation. *Sociology of Health and Illness*, 35(7), 1113–1127. https://doi.org/10.1111/1467-9566.12025
- Butler, C. (2013b). "University?... hell no!": Stammering through education. *International Journal of Educational Research*, *59*, 57–65. https://doi.org/10.1016/j.ijer.2013.03.002
- Caelli, K., Ray, L., & Mill, J. (2003). 'Clear as mud': toward greater clarity in generic qualitative research. *International journal of qualitative methods*, 2(2), 1-13.
- Callewaert, S. (2007). Kritiske refleksioner over den livshistoriske trend. In Petersen, A.K., S. Glasdam & V. Lorentzen (eds.) Livshistorieforskning og kvalitative interviews. Forlaget PUC, Viborg
- Carter, A. K., Breen, L. J., & Beilby, J. M. (2019). Self-efficacy beliefs: Experiences of adults who stutter. *Journal of Fluency Disorders*, 60(January), 11–25. https://doi.org/10.1016/j.jfludis.2019.03.002
- Carter, A., Breen, L., Yaruss, J. S., & Beilby, J. (2017). Self-efficacy and quality of life in adults who stutter. *Journal of Fluency Disorders*, *54*(June), 14–23. https://doi.org/10.1016/j.jfludis.2017.09.004
- Carver, C., Scheier, M., & Weintraub, J. (1989). Assessing Coping Strategies: A Theoretically Based Approach, Journal of Personality and Social Psychology. *Journal of Personality and Social Psychology*, 56(2), 267–283.
- Clark, C. (1987). Sympathy biography and sympathy margin. *American Journal of Sociology*, 93(2), 290-321.
- Clauson, G. M., & Kopatic, N. J. (1975). Teacher Attitudes and Knowledge of Remedial Speech Programs. Language, Speech, and Hearing Services in Schools, 6(4), 206-211. doi: 10.1044/0161-1461.0604.206
- Cohen, L., Manion, L., & Morrison, K. (2007). Research methods in education (6th ed.). London, UK: Routledge.
- Connery, A., McCurtin, A., & Robinson, K. (2019). The lived experience of stuttering: a synthesis of qualitative studies with implications for rehabilitation. *Disability and Rehabilitation*, 0(0), 1–11. https://doi.org/10.1080/09638288.2018.1555623
- Constantino, C. D., Manning, W. H., & Nordstrom, S. N. (2017). Rethinking covert stuttering. *Journal of Fluency Disorders*, *53*(June), 26–40. https://doi.org/10.1016/j.jfludis.2017.06.001
- Corcoran, J. A., & Stewart, M. (1998). Stories of stuttering: A qualitative analysis of

- interview narratives. *Journal of Fluency Disorders*, 23(4), 247–264. https://doi.org/10.1016/S0094-730X(98)00020-5
- Craig, A. (2010). The association between quality of life and stuttering.
- 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., Hancock, K., Tran, Y., Craig, M., & Peters, K. (2002). Epidemiology of stuttering in the community across the entire life span. *Journal of Speech, Language, and Hearing Research*, 45(6), 1097–1105. https://doi.org/10.1044/1092-4388(2002/088)
- Creswell, J. (2013). Qualitative inquiry and research design: Choosing among five approaches (3rd ed.). Thousand Oaks, CA: Sage.
- Crichton, S., & Childs, E. (2005). Clipping and Coding Audio Files: A Research Method to Enable Participant Voice. *International Journal of Qualitative Methods*, 4(3), 40–49. https://doi.org/10.1177/160940690500400303
- Crichton, S., & Childs, E. (2005). Clipping and Coding Audio Files: A Research Method to Enable Participant Voice. *International Journal of Qualitative Methods*, 4(3), 40–49. https://doi.org/10.1177/160940690500400303
- Crichton-Smith, I. (2002). Communicating in the real world: Accounts from people who stammer. *Journal of Fluency Disorders*, 27(4), 333–352. https://doi.org/10.1016/S0094-730X(02)00161-4
- Critical Appraisal Skills Programme Qualitative Checklist. (2018). Oxford (UK): CASP UK; [cited 2018 Jun 22]. Available from: https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist.pdf
- Daniels, D. E., & Gabel, R. M. (2004). The impact of stuttering on identity construction. *Topics in Language Disorders*, 24(3), 200-215.
- Daniels, D. E., Gabel, R. M., & Hughes, S. (2012). Recounting the K-12 school experiences of adults who stutter: A qualitative analysis. *Journal of Fluency Disorders*, 37(2), 71–82. https://doi.org/10.1016/j.jfludis.2011.12.001
- Daniels, D. E., Hagstrom, F., & Gabel, R. M. (2006). A qualitative study of how African American men who stutter attribute meaning to identity and life choices. *Journal of Fluency Disorders*, *31*(3), 200–215. https://doi.org/10.1016/j.jfludis.2006.05.002
- Davis, S., Howell, P., & Cooke, F. (2002). Sociodynamic relationships between children who stutter and their non-stuttering classmates. Journal of Child Psychology and Psychiatry, 43, 939–947.
- De Nil, L. F. (1999). Stuttering: A neurophysiologic perspective. *Stuttering Research* and *Practice: Bridging the Gap*, 85-102.
- Degroot, A. M., Dannenburg, L., & Vanhell, J. G. (1994). Forward and backward word translation by bilinguals. *Journal of memory and language*, *33*(5), 600-629.
- Denzin, N.K. (1992) Symbolic Interactionism and Cultural Studies: The Politics of

- Interpretation. Oxford: Blackwell.
- Earthy, S., & Cronin, A. (2008). Narrative nalysis.
- Ellis, A. Ls. in S. A. Q. S. of S. A. A. M. S. in E. S., & Hartlep, N. D. (2017). Struggling in Silence: A Qualitative Study of Six African American Male Stutterers in Educational Settings. *The Journal of Educational Foundations*, 30(1–4), 33–62. https://search.proquest.com/docview/2043654533?accountid=13828%0Ahttp://find.shef.ac.uk/openurl/44SFD/44SFD\_services\_page?url\_ver=Z39.88-2004&rft\_val\_fmt=info:ofi/fmt:kev:mtx:journal&genre=article&sid=ProQ:ProQ% 3Aeducation&atitle=Struggling+in+Silence%3A+
- Elsbach, K.D. and Bhattacharya, C.B. (2001) Defining who you are by what you're not: Organizational disidentification and the National Rifle Association, Organization Science, 12, 4, 393–413.
- Erickson, S., & Block, S. (2013). The social and communication impact of stuttering on adolescents and their families. *Journal of Fluency Disorders*, *38*(4), 311–324. https://doi.org/10.1016/j.jfludis.2013.09.003
- Ernest, P. (1994). Social constructivism and the psychology of mathematics education. *Constructing mathematical knowledge: Epistemology and mathematical education*, 62-71.
- Etchell, A. C., Civier, O., Ballard, K. J., & Sowman, P. F. (2018). A systematic literature review of neuroimaging research on developmental stuttering between 1995 and 2016. *Journal of Fluency Disorders*, *55*, 6–45. https://doi.org/10.1016/j.jfludis.2017.03.007
- Etherington, K. (2009). Life story research: A relevant methodology for counsellors and psychotherapists. *Counselling and Psychotherapy Research*, 9(4), 225–233. https://doi.org/10.1080/14733140902975282
- Evans, D., Healey, E. C., Kawai, N., & Rowland, S. (2008). Middle School students' perceptions of a peer who stutter. Journal of Fluency Disorders, 33, 203–219.
- Everard, R. A., & Howell, P. (2018). We have a voice: Exploring participants' experiences of stuttering modification therapy. *American Journal of Speech-Language Pathology*, 27(3S), 1273–1286. https://doi.org/10.1044/2018\_AJSLP-ODC11-17-0198
- Ezrati-Vinacour, R., & Weinstein, N. (2011). A dialogue among various cultures and its manifestation in stuttering therapy. *Journal of Fluency Disorders*, *36*(3), 174–185. https://doi.org/10.1016/j.jfludis.2011.01.004
- Fischer, W. (1982) Time and Chronic Illness. A Study on Social Constitution of Temporality, Berkeley (Habilitation thesis, University of Bielefeld).
- Folkman, S., & Lazarus, R. S. (1990). Coping and emotion. In N. L. Stein, B. Leventhal, & T. Trabasso (Eds.), Psychological and biological approaches to emotion (pp. 313–332). Hillsdale, NJ: Lawrence Erlbaum Associates, Publishers.
- Fraser, M. (2002). Self-therapy for the stutterer (No. 12). The Stuttering Foundation.
- Freud, D., & Amir, O. (2020). Resilience in people who stutter: Association with covert

- and overt characteristics of stuttering. *Journal of Fluency Disorders*, 64(March), 105761. https://doi.org/10.1016/j.jfludis.2020.105761
- GABEL, R. M. (2005). a Study of the Self-Talk of Adults Who Do and Do Not Stutter. *Perceptual and Motor Skills*, 92(3), 835. https://doi.org/10.2466/pms.92.3.835-842
- Gabel, R. M., Blood, G. W., Tellis, G. M., & Althouse, M. T. (2004). Measuring role entrapment of people who stutter. *Journal of Fluency Disorders*, 29(1), 27-49.
- García-Pastor, M. D., & Miller, R. (2019). Unveiling the needs of students who stutter in the language skills a study on anxiety and stuttering in EFL learning. *European Journal of Special Needs Education*, *34*(2), 172–188. https://doi.org/10.1080/08856257.2019.1581400
- Gauntlett D (2007) Creative Explorations: New Approaches to Identities and Audiences. Oxford: Routledge.
- General Authority for Statistics, Kingdom of Saudi Arabia (GSTAT). (2018). Retrieved 1 January 2021, from <a href="https://www.stats.gov.sa/en/904">https://www.stats.gov.sa/en/904</a>
- Gergen, K. J., & Davis, K. E. (Eds.). (1985). The social construction of the person. New York: Springer-Verlag.
- Gergen, K. J., & Gergen, M. (2008). *Social Construction Entering The Dialogue*. http://www.pdf.net/assets/uploads/publications/Social ConstructionTxt\_SAMPLE\_chp1.pdf
- Gergen, K. J., & Gergen, M. M. (2000). The New Aging: Self Construction and Social Values. *Social Structures and Aging*. https://doi.org/10.5066/F74J0C9Z
- Gergen, K.J. (1999). An invitation to social construction. London: Sage.
- Germeten, S. (2013). Personal Narratives in Life History Research. *Scandinavian Journal of Educational Research*, 57(6), 612–624. https://doi.org/10.1080/00313831.2013.838998
- Giddens, A. (1991) Modernity and Self-identity. Cambridge: Polity Press.
- Giele, J. Z., & Elder, G. H. (1998). Methods of life course research: Qualitative and quantitative approaches. Thousand Oaks, Calif.; London: Sage.
- Ginsberg, A. (2000). Shame, self-consciousness, and locus of control in people who stutter. The Journal of genetic psychology, 161(4), 389-399.
- Glover, H. L., St. Louis, K. O., & Weidner, M. E. (2019). Comparing stuttering attitudes of preschool through 5th grade children and their parents in a predominately rural Appalachian sample. *Journal of Fluency Disorders*, 59(October 2018), 64–79. https://doi.org/10.1016/j.jfludis.2018.11.001
- Goodson, I. & P. Sikes (2001). *Life history research in educational settings: learning from lives.* Open University Press, Buckingham
- Goodson, I. (2010). Key note presentation at 3:e konferensen om Livsberättelseforskning, 25-26 November, 2010 at Karlstad University
- Gordon, M. (2009). Toward a pragmatic discourse of constructivism: Reflections on lessons from practice. *Educational studies*, 45(1), 39-58.

- Gottwald, S.R., & Hall, N.E. (2003). Stuttering treatment in schools: Developing family and teacher partnerships. Seminars in Speech and Language 24(1), 40–46. http://dx.doi.org/10.1055/s-2003-37448
- Green, B. N., Johnson, C. D., & Adams, A. (2006). Writing narrative literature reviews for peer-reviewed journals: secrets of the trade. *Journal of chiropractic medicine*, 5(3), 101-117.
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. *Handbook of qualitative research*, 2(163-194), 105.
- Guitar, B. (2006). *Stuttering: An integrated approach to its nature and treatment* (3rd ed.). Baltimore, MD: Williams and Wilkins.
- Guitar, B. (2014). *Stuttering: An integrated approach to its nature and treatment*. Philadelphia, PA: Lippincott, Williams & Wilkins.
- Guttormsen, L. S., Kefalianos, E., & Næss, K. A. B. (2015). Communication attitudes in children who stutter: A meta-analytic review. *Journal of Fluency Disorders*, *46*, 1–14. https://doi.org/10.1016/j.jfludis.2015.08.001
- Hadidi, M. S., & Al Khateeb, J. M. (2015). Special Education in Arab Countries: Current challenges. *International Journal of Disability, Development and Education*, 62(5), 518–530. https://doi.org/10.1080/1034912X.2015.1049127
- Haidt, J., Koller, S., & Dias, M. (1993). Affect, culture, and morality, or is it wrong to eat your dog? Journal of Personality and Social Psychology, 65, 613–625. https://doi.org/10.1037/0022-3514.65.4.613
- Hamilton, R. J., & Bowers, B. J. (2006). Internet recruitment and e-mail interviews in qualitative studies. *Qualitative Health Research*, 16(6), 821–835. https://doi.org/10.1177/1049732306287599
- Hamoum,. M. (2016). 'athara aidtirabat alnatq ealaa eamaliat altelm: altashkhis waleilaj [The impact of speech skills on learning: diagnose and treatment]. Majallat Jīl al-'Ulūm al-Insānīyah wa-al-Ijtimā'īyah, 3, 71-83.
- Hanna, P. (2012). Using internet technologies (such as Skype) as a research medium: A research note. *Qualitative Research*, *12*(2), 239–242. https://doi.org/10.1177/1468794111426607
- Harrison, B. (2014). Life Story Research. In *Life Story Research*. https://doi.org/10.4135/9781446262368
- Hasnain, R., Shaikh, L. C., & Shanawani, H. (2008). Disability and the Muslim perspective: an introduction for rehabilitation and health care providers. *Buffalo*, *NY: Center for International Rehabilitation Research Information and Exchange*.
- Hayhow, R., Cray, A. M., & Enderby, P. (2002). Stammering and therapy views of people who stammer. *Journal of Fluency Disorders*, 27(1), 1–17. https://doi.org/10.1016/S0094-730X(01)00102-4
- Hertsberg, N., & Zebrowski, P. M. (2016). Self-perceived competence and social acceptance of young children who stutter: Initial findings. *Journal of Communication Disorders*, 64, 18–31. https://doi.org/10.1016/j.jcomdis.2016.08.004

- Holton, C., & Edmondson, D. R. (2015). Gilding the Lie: Using Brand Ambassadors to Capitalize on Negative Rumors About Their Organizations, an Initial Test of the Attitude Learning Model. In *Proceedings of the 2007 Academy of Marketing Science (AMS) Annual Conference* (pp. 34-36). Springer, Cham.
- Howell, K. E. (2013). *An introduction to the philosophy of methodology*. London: SAGE.
- Hughes, B. (2007). Being disabled: Towards a critical social ontology for disability studies. *Disability and Society*, 22(7), 673–684. https://doi.org/10.1080/09687590701659527
- Humeniuk, & Tarkowski, (2016). Parents' reactions to children's stuttering and style of coping with stress, J. Fluen. Disord. 49 (2016) 51–60.
- Hunter, S. (2010). Analysing and representing narrative data: The long and winding road. *Current Narratives*, *I*(2), 44.
- Hussein, M. H. (2010). The peer interaction in primary school questionnaire: Testing for measurement equivalence and latent mean differences in bullying between gender in Egypt, Saudi Arabia and the USA. *Social Psychology of Education*, 13(1), 57-76.
- Irani, F., & Gabel, R. (2008). Teachers' attitudes towards people who stutter: Results of a mail survey. Canadian Journal of Speech-Language Pathology and Audiology, 32, 129–134.
- Irani, F., Abdalla, F., & Gabel, R. (2012). *Arab and American Teachers' Attitudes Toward People Who Stutter:* 39, 12–20.
- Isaacs, D., & Swartz, L. (2020). "Stammering less so that I can be more of a man": Discourses of masculinities among young adult men in the Western Cape, South Africa, who stutter. *Psychology of Men & Masculinities*. https://doi.org/10.1037/men0000302
- Isaacs, D., & Swartz, L. (2020). Lived experience of people who stutter: a descriptive review of qualitative studies from 1990–2017. *Disability and Society*, 0(0), 1–19. <a href="https://doi.org/10.1080/09687599.2020.1735304">https://doi.org/10.1080/09687599.2020.1735304</a>
- Iser, M. (2013). *Recognition: Stanford Encyclopedia of Philosophy*. Edward N. Zalta (ed.). California: Stanford University. Retrieved from: <a href="https://plato.stanford.edu/entries/recognition/">https://plato.stanford.edu/entries/recognition/</a>
- Iverach, L., & Rapee, R. M. (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
- Jackson, E. S., Quesal, R., & Yaruss, J. S. (2012). What is stuttering: Revisited. In *International Stuttering Awareness Day Online Conference*.
- Jackson, E. S., Yaruss, J. S., Quesal, R. W., Terranova, V., & Whalen, D. H. (2015). Responses of adults who stutter to the anticipation of stuttering. In *Journal of Fluency Disorders* (Vol. 45, pp. 38–51). https://doi.org/10.1016/j.jfludis.2015.05.002

- Jake M. Laguado. (2014). Cooperative Learning Approach in An Outcome -based Environment. *International Journal of Social Sciences, Arts and Humanities*, 2(2), 46–55.
- Jenkins, H. (2010). Attitudes of teachers towards dysfluency training and resources. International Journal of Speech-Language Pathology, 12, 253–258.
- Johnson, J. C., Avenarius, C., & Weatherford, J. (2006). The active participant—observer: Applying social role analysis to participant observation. Field Methods, 18, 111–134.
- Jones, E., Gallois, C., Callan, V., & Barker, M. (1999). Strategies of accommodation: Development of a coding system for conversational interaction. Journal of Language and Social Psychology, 18(2), 123–52.
- Kang, C., Riazuddin, S., Mundorff, J., Krasnewich, D., Friedman, P., Mullikin, J., et al. (2010). Mutations in the lysosomal enzyme-targeting pathway and persistent stuttering. New England Journal of Medicine, 362, 677–685.
- Kathard, H. (2001). Sharing Stories: Life History Narratives in Stuttering Research. *International Journal of Language & Communication Disorders*, *36*(s1), 52–57. https://doi.org/10.3109/13682820109177858
- Kathard, H. (2003). On Becoming Someone. March.
- Kathard, H. (2009). Personal truth making. A cautious celebration. In R. Dhanpath & M. Samuel (Eds.), Life history research: Epistemology, methodology and representation (pp. 18-36). Rotterdam: Sense Publishers.
- Kathard, H., Norman, V., & Pillay, M. (2010). Configurations of self-identity formations of adults who stutter. *South African Journal of Communication Disorders*, *57*(1), 51–57. https://doi.org/10.4102/sajcd.v57i1.49
- Kawai, N., Healey, E. C., Nagasawa, T., & Vanryckeghem, M. (2012). Communication attitudes of Japanese school-age children who stutter. *Journal of Communication Disorders*, 45(5), 348–354. https://doi.org/10.1016/j.jcomdis.2012.05.004
- Kesby M (2000) Participatory diagramming: deploying qualitative methods through an action research epistemology. Area 32(4): 423–435.
- Khatib, S. A. A. (1997). The social status of women in traditional Saudi society. *J Humanit Soc Sci. UAE Univ*, 2, 23-47.
- 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
- Koedoot, C., Bouwmans, C., Franken, M. C., & Stolk, E. (2011). Quality of life in adults who stutter. *Journal of Communication Disorders*, *44*(4), 429–443. https://doi.org/10.1016/j.jcomdis.2011.02.002
- Koutsodimitropoulos, E., Buultjens, M., Louis, K. O., & Monfries, M. (2016). Speech pathology student clinician attitudes and beliefs towards people who stutter: A mixed-method pilot study. *Journal of Fluency Disorders*, 47, 38–55.

- https://doi.org/10.1016/j.jfludis.2015.12.003
- Krummenacher, R., & Strang, T. (2007). Ontology-Based Context Modeling. *Ieice Transactions On Information And Systems*, *E90-D*(8), 1262–1270. https://doi.org/10.1093/ietisy/e90-d.8.1262
- Kumar, A. S., & Varghese, A. L. (2018). A study to assess awareness and attitudes of teachers towards primary school children with stuttering in Dakshina Kannada District, India. *Journal of Clinical and Diagnostic Research*, *12*(9), JC09-JC13. https://doi.org/10.7860/JCDR/2018/35202.12030
- Kvale, S. (1996) Interviews. London: Sage.
- Kvale, S. (2007). Doing Interviews. Introduction to interview research. London: Sage.
- Laird, J. (Ed.). (1993). Revisioning social work education: A social constructionist approach. New York: The Haworth Press.
- Lakey, B., & Cohen, S. (2000). Social support and theory. Social Support Measurement and Intervention: A guide for health and social scientists. New York, NY: Oxford University Press
- Langevin, M. (2015). Bullying experienced by youth who stutter: the problem and potential intervention strategies. *Stuttering meets stereotype, stigma and discrimination: an overview of attitude research. West Virginia University*, 71-90.
- Langevin, M., & Prasad, N. G. N. (2012). A Stuttering Education and Bullying Awareness and Prevention Resource: A Feasibility Study. *Language, Speech, and Hearing Services in Schools*, 43(3), 344–358. https://doi.org/10.1044/0161-1461(2012/11-0031)
- Langevin, M., Packman, A., & Onslow, M. (2009). Peer responses to stuttering in the preschool setting. American Journal of Speech-Language Pathology, 18, 264–276.
- Langevin, M., Packman, A., & Onslow, M. (2010). Parent perceptions of the impact of stuttering on their preschoolers and themselves. *Journal of Communication Disorders*, 43(5), 407–423. https://doi.org/10.1016/j.jcomdis.2010.05.003
- Lass, N. J., Ruscello, D. M., Schmitt, J. F., Pannbacker, M. D., Orlando, M. B., Dean, K. A., . . . Bradshaw, K. H. (1992). Teachers' Perceptions of Stutterers. Language, Speech, and Hearing Services in Schools, 23(1), 78-81. doi: 10.1044/0161-1461.2301.73
- Lawrence, P. (2018). A narrative approach to coaching multiple selves. *International Journal of Evidence Based Coaching and Mentoring*, 16(2), 32–41. https://doi.org/10.24384/000564
- Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal, and coping. New York, NY: Springer Publishing Company.
- Leahy, M. M., O'Dwyer, M., & Ryan, F. (2012). Witnessing stories: Definitional Ceremonies in Narrative Therapy with adults who stutterImpact of stuttering. *Journal of Fluency Disorders*, *37*(4), 234–241. https://doi.org/10.1016/j.jfludis.2012.03.001
- Lee, K. (2014). Korean speech-language pathologists' attitudes toward stuttering

- according to clinical experiences. *International Journal of Language and Communication Disorders*, 49(6), 771–779. <a href="https://doi.org/10.1111/1460-6984.12093">https://doi.org/10.1111/1460-6984.12093</a>
- Lee, K., 2013, Perception toward stuttering by teachers in Daegu area. Communication Sciences and Disorders, 18, 447–458.
- Leon-Sarmiento, F. E., Paez, E., & Hallett, M. (2013). Nature and nurture in stuttering: a systematic review on the case of Moses. *Neurological Sciences*, *34*(2), 231–237. https://doi.org/10.1007/s10072-012-0984-2
- Lincoln, Y., & Guba, E. (1985). Naturalistic inquiry. Beverly Hills, CA: Sage
- Lit, S., & Shek, D. T. L. (2002). Implications of Social Constructionism to Counseling and Social Work Practice. *Asian Journal of Counselling*, 9(1 & 2), 105–130.
- Livholts, M., & Tamboukou, M. (2015). Discourse and narrative methods. Thousand Oaks, CA: Sage.
- Lowe, R., Guastella, A. J., Chen, N. T. M., Menzies, R. G., Packman, A., O'Brian, S., & Onslow, M. (2012). Avoidance of eye gaze by adults who stutter. *Journal of Fluency Disorders*, *37*(4), 263–274. https://doi.org/10.1016/j.jfludis.2012.04.004
- Mack, L. (2010). The philosophical underpinnings of educational research.
- Mann, C., & Stewart, F. (2000). Internet communication and qualitative research. Thousand Oaks, CA: Sage.
- Mason, J. (2002). Qualitative researching (2nd ed. ed.). London: SAGE.
- Mason, J. (2002). Qualitative researching (2nd ed.). London: Sage.
- Maxfield, N. D., & Ferreira, F. (2019). Backward-looking sentence processing in typically disfluent versus stuttered speech: ERP evidence. *Language, Cognition and Neuroscience*, *34*(5), 561–579. https://doi.org/10.1080/23273798.2018.1533140
- Maxwell, D. L. (1982). Cognitive and behavioral self-control strategies: Applications for the clinical management of adult stutterers. *Journal of Fluency Disorders*, 7(4), 403-432.
- McAdams, D. P. (1993). The stories we live by: Personal myths and the making of the self. Guilford Press.
- McAdams, D. P. (2013). The redemptive self: Stories Americans live by (Rev. ed.). New York, NY: Oxford University Press.
- McAllister, J. (2016). Behavioural, emotional and social development of children who stutter. *Journal of Fluency Disorders*, *50*, 23–32. https://doi.org/10.1016/j.jfludis.2016.09.003
- 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

- McIntosh, M. J., & Morse, J. M. (2015). Situating and constructing diversity in semi-structured interviews. *Global qualitative nursing research*, 2, 2333393615597674.
- McKinnon, D. H., McLeod, S., & Reilly, S. (2007). The prevalence of stuttering, voice, and speech-sound disorders in primary school students in Australia. *Language*, *Speech, and Hearing Services in Schools*, *38*(1), 5–15. https://doi.org/10.1044/0161-1461(2007/002)
- Meline, T. (2006). Selecting Studies for Systemic Review: Inclusion and Exclusion Criteria. *Contemporary Issues in Communication Science and Disorders*, 33(Spring), 21–27. https://doi.org/10.1044/cicsd\_33\_s\_21
- Messenger, M., Onslow, M., Packman, A., & Menzies, R. (2004). Social anxiety in stuttering: Measuring negative social expectancies. *Journal of Fluency Disorders*, 29(3), 201–212. https://doi.org/10.1016/j.jfludis.2004.06.002
- Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. Journal of Counseling Psychology, 52, 2, 250-260.
- Mulcahy, K., Hennessey, N., Beilby, J., & Byrnes, M. (2008). Social anxiety and the severity and typography of stuttering in adolescents. *Journal ofFluency Disorders*, 33, 306–319.
- Murphy, B., Quesal, R., & Gulker, H. (2007). Covert stuttering. *Perspectives on Fluency and Fluency Disorders*, 17, 4–9.
- Nang, C., Hersh, D., Milton, K., & Lau, S. R. (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. <a href="https://doi.org/10.1044/2018\_AJSLP-ODC11-17-0201">https://doi.org/10.1044/2018\_AJSLP-ODC11-17-0201</a>
- Nang, C., Reynolds, V., Hersh, D., Andrews, C., & Humphries, O. (2019). The experiences of migrants to Australia who stutter. *Journal of Fluency Disorders*, 62(September), 105723. https://doi.org/10.1016/j.jfludis.2019.105723
- Neimeyer, R. A. (2002). The relational co-construction of selves: A postmodern perspective. Journal ofContemporary Psycho- therapy, 32(1), 51–59
- Nippold, M. A., & Packman, A. (2012). Managing stuttering beyond the preschool years. *Language, Speech, and Hearing Services in Schools*, 43(3), 338–343. https://doi.org/10.1044/0161-1461(2012/12-0035)
- 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
- O'Dwyer, M., Walsh, I. P., & Leahy, M. M. (2018). The Role of Narratives in the Development of Stuttering as a Problem. 27(October), 1164–1179.
- Oliver, M. (1996), *Understanding Disability: from Theory to Practice*, Macmillan, London.

- Oliver, M. (2013). *The social model of disability: thirty years on.* Disability & Society, 28(7), 1024-1026.
- Özdemir, R. S., St. Louis, K. O., & Topbaş, S. (2011). Public attitudes toward stuttering in Turkey: Probability versus convenience sampling. *Journal of Fluency Disorders*, 36(4), 262–267. https://doi.org/10.1016/j.jfludis.2011.01.003
- Pachigar, V., Stansfield, J., & Goldbart, J. (2011). Beliefs and Attitudes of Primary School Teachers in Mumbai, India Towards Children Who Stutter. International Journal of Disability, Development and Education, 58(3), 287-302. doi: 10.1080/1034912x.2011.598664
- Pachigar, V., Stansfield, J., & Goldbart, J. (2011). Beliefs and attitudes of primary school teachers in Mumbai, India towards children who stutter. International Journal of Disability, Devel-opment and Education, 58, 287–302
- Panico, J., Healey, E. C., Brouwer, K., & Susca, M. (2005). Listener perceptions of stuttering across two presentation modes: A quantitative and qualitative approach. *Journal of Fluency Disorders*, *30*(1), 65–85. https://doi.org/10.1016/j.jfludis.2005.01.003
- Percy, W. H., Kostere, K., & Kostere, S. (2015). Generic qualitative research in psychology. *The qualitative report*, 20(2), 76-85.
- Pierre, J. S. (2012). The construction of the disabled speaker: Locating stuttering in disability studies. *Canadian Journal of Disability Studies*, 1(3), 1-21.
- 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(March 2018), 52–63. https://doi.org/10.1016/j.jfludis.2018.10.004
- Plexico, L. W., Manning, W. H., & Levitt, H. (2009a). Coping responses by adults who stutter: Part I. Protecting the self and others. *Journal of Fluency Disorders*, *34*(2), 87–107. https://doi.org/10.1016/j.jfludis.2009.06.001
- Plexico, L., Manning, W. H., & Dilollo, A. (2005). A phenomenological understanding of successful stuttering management. *Journal of Fluency Disorders*, *30*(1), 1–22. https://doi.org/10.1016/j.jfludis.2004.12.001
- Plexico, L., Manning, W. H., & Levitt, H. (2009b). Coping responses by adults who stutter: Part II. Approaching the problem and achieving agency. *Journal of Fluency Disorders*, *34*(2), 108–126. https://doi.org/10.1016/j.jfludis.2009.06.003
- Plummer, K. (1990). Herbert Blumer and the Life History Tradition. *Symbolic Interaction*, 13(2), 125–144. https://doi.org/10.1525/si.1990.13.2.125
- Plummer, K. (1995). 'Life Story Research', in Rethinking methods in psychology, eds J.A. Smith, R Harre &L. Van Langenhove, Sage Publications, London, pp. 50-63.
- Plummer, K. (2001). Documents of life 2. London: Sage.
- Plummer, K. (2005). *Documents of life 2: an invitation to critical humanism.* Sage Publications, Tyne & Wear

- Prasse, J. e., & KiKano, G. e. (2008). Stuttering: An Overview.
- Pratkanis, A. R., Breckler, S. J., & Greenwald, A. G. (Eds.). (2014). *Attitude structure and function*. Psychology Press.
- Przepiorka, A. M., Blachnio, A., St. Louis, K. O., & Wozniak, T. (2013). Public attitudes toward stuttering in Poland. *International Journal of Language and Communication Disorders*, 48(6), 703–714. https://doi.org/10.1111/1460-6984.12041
- Read, J.G. & Bartkowski, J.P. (2000) To veil or not to veil? A case study of identity negotiation among muslim women in Austin, Texas, Gender and Society, 14, 3, 395–417.
- Reindal, S. M. (2008). A social relational model of disability: A theoretical framework for special needs education? *European Journal of Special Needs Education*, 23(2), 135–146. https://doi.org/10.1080/08856250801947812
- Reindal, S. M. (2010). Redefining disability: a rejoinder to a critique. *Etikk i Praksis Nordic Journal of Applied Ethics*, *4*(1), 125–135. https://doi.org/10.5324/eip.v4i1.1744
- Rich, H. (2018). ETHICAL GUIDELINES FOR EDUCATIONAL RESEARCH. *British Educational Research Association (BERA)*, *38*(2), 160. https://doi.org/10.1080/00031305.1984.10483191
- Riessman, C. K., & Quinney, L. (2005). Narrative in social work: A critical review. *Qualitative social work*, 4(4), 391-412.
- Robson, C. (2002). Real world research. Oxford, Oxfordshire: Blackwell Publishers.
- Roeser, R. W., Eccles, J. S., & Freedman-Doan, C. (1999). Academic functioning and mental health in adolescence: Patterns, progressions, and routes from childhood. *Journal of Adolescent Research*, *14*(2), 135-174.
- Rosenthal G a& Fisher-Rosenthal W. (2004). 'The analysis of narrative-biographical interviews' in U Flick, E von Kardorff and I Steinke (eds) A Companion to Qualitative Research Sage Publications, London: 259-65
- Rosenthal, G. (1993). Reconstruction of life stories: principles of selection in generating stories for narrative biographical interviews. *The Narrative Study of Lives 1*, *I*(1), 59–91.
- Rosenthal, G. (1995). Erlebte und erzählte Lebensgeschichte. Gestalt und Struktur biographischer Selbstbeschreibungen, Frankfurt a. M., Campus.
- Rosenthal, G. (2006). The Narrated Life Story: On the Interrelation Between Experience, Memory and Narration. *Narrative, Memory & Knowledge: Representations, Aesthetics, Contexts*, 1–16. https://doi.org/10.1590/S0104-83332006000100007
- Rosner, R. L. 2000. "The Dreaded Oral Presentation." Accounting Education 9 (4): 409–411. doi:10.1080/09639280010056217.
- Ryan, G.W., & Bernard, H.R. (2003). Techniques to identify themes. Field Methods 15(1), 85–109.

- Safwat, R., & Sheikhany, A. (2014). Parental attitudes and knowledge of stuttering. *The Egyptian Journal of Otolaryngology*, 30(2), 151–151. http://go.galegroup.com/ps/i.do?p=AONE&sw=w&u=rdg&v=2.1&it=r&id=GALE %7CA394270006&sid=classroomWidget&asid=ca4e7597#.XN1hiRfDtCo.mendel ey
- Saldaña, J. (2013). The Coding Manual for Qualitative Researchers (2nd Ed.). In *SAGE Publications Inc.* https://doi.org/10.1017/CBO9781107415324.004
- Salehpoor, A., Latifi, Z., & Tohidast, S. A. (2020). Evaluating parents' reactions to Children's stuttering using a Persian version of reaction to Speech Disfluency Scale. *International Journal of Pediatric Otorhinolaryngology*, *134*(April). https://doi.org/10.1016/j.ijporl.2020.110076
- Saunders, M., Lewis, P., & Thornhill, A. (2009). Research methods for business students, 5/e. Edinburgh: Pearson Education Limited.
- Saunders, M., Lewis, P., & Thornhill, A. (2012). Research methods for business students (6. utg.). *Harlow: Pearson*.
- Scharf, E. S. (2017). "Exploring the Lived Experiences of Adults Who Stutter: A Qualitative Study." Ursidae: *The Undergraduate Research Journal at the University of Northern Colorado* 6 (3): 1–37.
- Schönfelder, W. (2011). CAQDAS and Qualitative Syllogism Logic NVivo 8 and MAXQDA 10 Compared. *Qualitative Sozialforschung / Forum: Qualitative Social Research*, 12(1), Art. 21.
- Seale, C. (1999). Quality in qualitative research. *Qualitative inquiry*, 5(4), 465-478.
- Shakespeare, T. (1994). Cultural Representation of Disabled People: Dustbins for disavowal? *Disability & Society*, *9*(3), 283–299. https://doi.org/10.1080/09687599466780341
- Shakespeare, T., & Watson, N. (1997). Defending the social model. *Disability and Society*, *12*(2), 293–300. https://doi.org/10.1080/09687599727380
- Shakespeare, T., & Watson, N. (2002). The social model of disability: an outdated ideology? (This article appeared in the Journal '. *Research in Social Science and Disability*, 2, 9–28.
- Sheridan, J., Chamberlain, K., & Dupuis, A. (2011). Timelining: Visualizing experience. *Qualitative Research*, 11(5), 552–569. https://doi.org/10.1177/1468794111413235
- Sijeeni, A. (2016). Understanding the experiences of mothers caring for children with Down Syndrome in Saudi Arabia. http://eprints.qut.edu.au/98052/ [April 20, 2017]
- Silverman, H. (2017). Ethical Issues in Social and Behavioural Research. In *Research Ethics in the Arab Region* (pp. 117-131). Springer, Cham.
- Singer, J. A., Blagov, P., Berry, M., & Oost, K. M. (2013). Self-Defining Memories, Scripts, and the Life Story: Narrative Identity in Personality and Psychotherapy. *Journal of Personality*, 81(6), 569–582. https://doi.org/10.1111/jopy.12005
- Smith, J. A., P. Flowers, and M. Larkin. (2009). Interpretative Phenomenological

- Analysis: Theory, Method and Research. London: Sage.
- Smith, L., & Abouammoh, A. (2013). *Higher Education Dynamics 40 Higher Education in Saudi Arabia*. http://www.springer.com/series/6037
- Snyder, G. J. (2001). Exploratory research in the measurement and modification of attitudes toward stuttering. Journal of Fluency Disorders, 26(2), 149–160.
- St Louis, K. O., Sønsterud, H., Carlo, E. J., Heitmann, R. R., & Kvenseth, H. (2014). Public attitudes toward-and identification of-cluttering and stuttering in Norway and Puerto Rico. *Journal of Fluency Disorders*, 42(1), 21–34. https://doi.org/10.1016/j.jfludis.2014.05.005
- St Pierre, J. (2017). Becoming Dysfluent: Fluency as Biopolitics and Hegemony. *Journal of Literary & Cultural Disability Studies*, 11(3), 339-356,383. https://doi.org/http://dx.doi.org/10.3828/jlcds.2017.26
- St. Louis, K. O. (2005). A global project to measure public attitudes of stuttering. Asha Leader, 10(12(3)), 22.
- St. Louis, K. O. (2011). The Public Opinion Survey of Human Attributes-Stuttering (POSHA-S): summary framework and empirical comparisons. Journal of Fluency Disorders, 36, 256-261
- St. Louis, K. O., & Roberts, P. M. (2010). Measuring attitudes toward stuttering: English-to-French translations in Canada and Cameroon. Journal of Communication Disorders, 43, 361–377.
- St. Louis, K. O., Irani, F., Gabel, R. M., Hughes, S., Langevin, M., Rodriguez, M., Scott, K. S., & Weidner, M. E. (2017). Evidence-based guidelines for being supportive of people who stutter in North America. *Journal of Fluency Disorders*, 53(January), 1–13. https://doi.org/10.1016/j.jfludis.2017.05.002
- St. Louis, K. O., Sønsterud, H., Junuzović-Žunić, L., Tomaiuoli, D., Del Gado, F., Caparelli, E., Theiling, M., Flobakk, C., Helmen, L. N., Heitmann, R. R., Kvenseth, H., Nilsson, S., Wetterling, T., Lundström, C., Daly, C., Leahy, M., Tyrrell, L., Ward, D., & Wesierska, M. (2016). Public attitudes toward stuttering in Europe: Within-country and between-country comparisons. *Journal of Communication Disorders*, 62, 115–130. https://doi.org/10.1016/j.jcomdis.2016.05.010
- St. Louis, K. O., Williams, M. J., Ware, M. B., Guendouzi, J., & Reichel, I. K. (2014). The Public Opinion Survey of Human Attributes-Stuttering (POSHA-S) and Bipolar Adjective Scale (BAS): Aspects of validity. *Journal of Communication Disorders*, 50, 36–50. https://doi.org/10.1016/j.jcomdis.2014.04.001
- St. Louis, K.O., Weidner, M.E., & Mancini, T.M. (2016). Comparing parents' and young children's attitudes toward stuttering. Journal of Speech Pathology & Therapy, 1, 104. https://doi.org/10.4172/2472-5005.1000104
- Stewart, T., & Richardson, G. (2004). A qualitative study of therapeutic effect from a user's perspective. *Journal of Fluency Disorders*, 29(2), 95–108. https://doi.org/10.1016/j.jfludis.2003.11.001
- Stoudt, B. G., & Ouellette, S. C. (2004). Making room for words: People who stutter on

- the Internet. *Qualitative Research in Psychology*, *1*(3), 175–194. https://doi.org/10.1191/1478088704qp013oa
- Strauss, A., & Corbin, J. (1990). Basics of qualitative research. London: Sage.
- Sturges JE & Hanrahan KJ .(2004). Comparing telephone and face-to-face qualitative interviewing: a research note. Qualitative Research in Psychology 4: 107–118.
- 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
- Takeda, T., Nakataki, M., Ohta, M., Hamatani, S., Matsuura, K., Yoshida, R., Kameoka, N., Tominaga, T., Umehara, H., Kinoshita, M., Watanabe, S., Numata, S., Sumitani, S., & Ohmori, T. (2019). Negative and positive self-thoughts predict subjective quality of life in people with schizophrenia. *Neuropsychiatric Disease and Treatment*, 15, 293–301. https://doi.org/10.2147/NDT.S190381
- Tamboukou, M. (2010). Relational narratives: Auto/biography and the portrait. Women's Studies International Forum, 33(3), 170–179. https://doi.org/10.1016/j.wsif.2009.12.007
- Teesson, K., Packman, A., & Onslow, M. (2006). The Lidcombe Behavioral Data Language of Stuttering. *Journal of Speech, Language, and Hearing Research*, 46(4), 1009–1015. https://doi.org/10.1044/1092-4388(2003/078)
- Thabane, L., Ma, J., Chu, R., Cheng, J., Ismaila, A., Rios, L. P., ... & Goldsmith, C. H. (2010). A tutorial on pilot studies: the what, why and how. *BMC medical research methodology*, 10(1), 1-10.
- Thomas, C. (2004). Rescuing a social relational understanding of disability. *Scandinavian Journal of Disability Research*, *6*(1), 22–36. https://doi.org/10.1080/15017410409512637
- Thomas, C., Hatton, C., Graham, H., Atkin, K., & Berghs, M. (2016). Implications for public health research of models and theories of disability: A scoping study and evidence synthesis.
- Thomson R & Holland J .(2005). 'Thanks for the memory': memory books as a methodological resource in biographical research. Qualitative Research 5(2): 201–219.
- Tichenor, S., & 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\_AJSLP-ODC11-17-0192
- Titchkosky, T. (2003). *Disability, Self, and Society*. Toronto, ON: University of Toronto Press.
- Tudor, H., Davis, S., Brewin, C. R., & Howell, P. (2013). Recurrent involuntary imagery in people who stutter and people who do not stutter. *Journal of Fluency Disorders*, 38(3), 247–259. https://doi.org/10.1016/j.jfludis.2013.06.003
- Van Lieshout, P., Ben-David, B., Lipski, M., & Namasivayam, A. (2014). The impact of threat and cognitive stress on speech motor control in people who stutter. Journal of Fluency Disorders, 40, 93–109.

- Vanryckeghem, M., Brutten, G. J., Uddin, N., & Van Borsel, J. (2004). A comparative investigation of the speech-associated coping responses reported adults who do and do not stutter. Journal ofFluency Disorders, 29, 237–250.
- Walden, T. A., & Lesner, T. A. (2018). Examining implicit and explicit attitudes toward stuttering. *Journal of Fluency Disorders*, *57*(June), 22–36. https://doi.org/10.1016/j.jfludis.2018.06.001
- Walden, T. A., Lesner, T. A., & Jones, R. M. (2020). Is what I think I think really what I think? Implicit and explicit attitudes toward stuttering among practicing speech-language pathologists. *Journal of Communication Disorders*, 83(November 2018), 105965. https://doi.org/10.1016/j.jcomdis.2019.105965
- Wang, W. L., Lee, H. L., & Fetzer, S. J. (2006). Challenges and strategies of instrument translation. *Western Journal of Nursing Research*, 28(3), 310-321.
- Watson, T. J. (2009). Narrative, life story and manager identity: A case study in autobiographical identity work. *Human Relations*, 62(3), 425–452. https://doi.org/10.1177/0018726708101044
- Weidner, M. E., St. Louis, K. O., & Glover, H. L. (2018). Changing Nonstuttering Preschool Children's Stuttering Attitudes. *American Journal of Speech-Language Pathology*, 27(4), 1445–1457. https://doi.org/10.1044/2018\_ajslp-18-0019
- Weidner, M. E., St. Louis, K. O., Nakisci, E., & Ozdemir, R. S. (2017). A comparison of attitudes towards stuttering of non-stuttering preschoolers in the United States and Turkey. *South African Journal of Communication Disorders*, *64*(1), 1–11. https://doi.org/10.4102/sajcd.v64i1.178
- Weidner, M.E., St. Louis, K.O., Burgess, M.E., & LeMasters, S.N. (2015). Attitudes toward stuttering of nonstuttering preschool and kindergarten children: A comparison using a standard instrument prototype. Journal of Fluency Disorders, 44, 74–87. https://doi.org/10.1016/j.jfludis.2015.03.003
- Wesierska, K., & Przepiorka, A. (2019). Success in changing stuttering attitudes: A retrospective analysis of 29 intervention studies. January 2020. https://doi.org/10.1016/j.jcomdis.2019.105972
- Wheeldon, J. (2011). Is a picture worth a thousand words? Using mind maps to facilitate participant recall in qualitative research. *Qualitative Report*, 16(2), 509–522.
- Wheeldon, J., & Faubert, J. (2009). Framing Experience: Concept Maps, Mind Maps, and Data Collection in Qualitative Research. *International Journal of Qualitative Methods*, 8(3), 68–83. https://doi.org/10.1177/160940690900800307
- Wilson S, Cunningham-Burley S, Bancroft A, Backett-Milburn K and Masters H (2007) Young people, biographical narratives and the life grid: young people's accounts of parental substance use. Qualitative Research 7(1): 135–151.
- Woods, C. L. (1975). Teachers' Predictions of the Social Position and Speaking Competence of Stuttering Students. Language, Speech, and Hearing Services in Schools, 6(4), 177-182.
- Yaruss, J. S. (2010). Assessing quality of life in stuttering treatment outcomes research.

- *Journal of Fluency Disorders*, *35*(3), 190–202. https://doi.org/10.1016/j.jfludis.2010.05.010
- Yaruss, J. S., & Quesal, R. W. (2004). Stuttering and the International Classification of Functioning, Disability, and Health (ICF): An update. *Journal of Communication Disorders*, *37*(1), 35–52. https://doi.org/10.1016/S0021-9924(03)00052-2
- Yaruss, J. S., & Quesal, R. W. (2006). Overall Assessment of the Speaker's Experience of Stuttering (OASES): Documenting multiple outcomes in stuttering treatment. *Journal of Fluency Disorders*, 31(2), 90–115. https://doi.org/10.1016/j.jfludis.2006.02.002
- Yaruss, J. S., Murphy, W. P., Quesal, R. W., & Reardon, N. A. (2004). Bullying and teasing: Helping children who stutter. *New York: National Stuttering Association*.
- Yeakle, M. K., & Cooper, E. B. (1986). Teacher perceptions of stuttering. Journal of Fluency Disorders, 11(4), 345-359. doi: 10.1016/0094-730x(86)90022-7

# Appendices

**Appendix A: Studies Concerning Lived Experience of Stuttering** 

Study and	Subject	Research	Major idea	Findings
-	Subject	method	relating to	rinanigs
country				
		and results	stuttering	
			experience and	
			Theoretical	
			framework	
Beilby,	The individual	Two	People who	The two groups did
Byrnes,	experience of	questionnair	stutter (PWS) and	not show that QoL
Meagher	how quality of	es, as well	relatives' QoL in	and stuttering were
and	life (QoL) is	as semi-	relation to	linked, although
Yaruss	affected by	structured	stuttering	PWS and spouses'
2013	stuttering,	qualitative		communication were
Australia	alongside its	interviews	Theoretical	both affected by
	effect on spousal		framework:	stuttering
	relationships		Medical mode of	
			disability and	
			grounded theory	
Bricker-	How PWS'	Interviews	PWS' lives are	Work experiences
Katz,	work	with three	affected by	have been
Lincoln and	experiences	women and	stuttering. PWS'	detrimentally
Cumming	been affected by	six men	development of	affected by stuttering
2013	stuttering,	(nine PWS	self-stigma and	,
Australia	alongside the	in total)	negative societal	
	meaning of such	·	attitudes are	
	experiences for		connected as an	
	PWS		internal dynamic	
			•	
			Theoretical	
			framework: The	
			social model and	
			social	
			interactional	
			model	
Bricker-	Stuttering's	Focus group	How the social	Just as with young
Katz,	effect on	qualitative	interaction of	PWS,
Lincoln and	communication,	research	individuals is	communication
McCabe	as well as	involving	affected by	problems are faced
2010	stuttering	three female	stuttering	by mature PWS
Australia	interventions'	and eight	Theoretical	•
	effectiveness,	male PWS.	framework:	
	from the		Attitudes theory	
	perspective of		and cognitive	
	mature PWS,		theory; World	
	,		Health	
			Organization	
			International	

Butler, 2013a UK	Through investigating how PWS are afflicted by occasional development of prejudiced perspectives, the study determines how PWS' identify formation is affected and how they manage such perspectives. Therefore, the identity discussion is furthered by this study	38 PWS were involved in semi- structured interviews and focus group discussions	Classification of Function, Disability and Health (ICF) Because the communicative norm is not reflected by the speech of PWS, they typically confront prejudice and marginalisation Theoretical framework: Social identity theory	The social space is utilised variedly by PWS, based on their explanation of stuttering management. For example, their stutter is obscured in the social space, or it provides an alternative space for speech acts, or a pause where they can change words
Carter, Breen and Beilby 2019 Australia	Investigation of adult PWS' perspectives of their self-efficacy, so that comprehensive and efficient interventions could be developed for them	29 PWS participated in semi-structured interviews	PWS' adherence to treatment, resilience and QoL are significantly affected by self-efficacy  Theoretical framework: Self-Efficacy Theory and Social Cognitive Theory	Adult PWS' experiences of self- efficacy attitudes are intricate, with original understanding offered by the concepts of the study. The dominant impact of self, alongside personal attitudes, influenced communicative confidence; fluency was not the sole factor considered as defining stuttering; fluency and communication were perceived as being at-odds; communicative confidence was influenced by the

				experiences of the
Carter, Breen, Yaruss and Beilby 2017 Australia and USA	Stuttering experience and self-efficacy's interaction	Mixed methods research. 39 adult PWS' completion of the	Personal stuttering experiences are informed by self- conception and self-efficacy.	PWS  QoL is connected to self-efficacy. Self-efficacy is negatively correlated to stuttering regularity.
		Overall Assessment of the Speaker's Experience with Stuttering and adoption of the Self- Efficacy Scale. Semi- structured interviews with ten participants	Self-efficacy is affected by the stutter's intensity  Theoretical framework: Self-attitudes and cognitive theory	Distinctive personal experiences shape PWS
Crichton- Smith 2002 UK	The coping approaches and communicative experiences of stuttering among PWS	14 adult PWS participated in in-depth interviews	PWS' lives are restricted by stuttering, including their personal confidence, as well as social and educational experiences. The experiences of PWS are improved through coping mechanisms  Theoretical framework: Contextual Model of Coping	The experiences of individuals are restricted by stuttering. Managing circumstances is undertaken using avoidance. Various communication management approaches are implemented
Daniels, Gabel and Hughes 2012 USA	Adult PWS' previous school life	21 adult participants in total. Two focus groups were held with	Theoretical framework: Coping Theory and Grounded Theory	Both social and academic participation is necessary for learners within the intricate cultural

		six and four participants respectively . 3 women and 8 men participated in semi- structured interviews.		context of the school.
Daniels, Hagstrom and Gabel 2006 USA	Perceptions of life decisions, identity and communication among male African American PWS	Six male PWS participated in semi- structured interviews	Theoretical framework: constructivist philosophy, Grounded Theory, to investigate perceptions of life decisions, identity and communication among PWS	Perceptions of life decisions, their stutter and of themselves were all impacted by culture, ethnicity, communication and the interplay between them
Ellis and Hartlep 2017 USA	Male African American PWS' educational experiences	Life History Method involving six male African American PWS	Within school, challenges over identity and affliction with stereotypes are both hazards for learners linked to stuttering	Especially within the school environment, male African American PWS were markedly affected by stuttering. The PWS' career management and self-identities were affected by stuttering
Kathard, Norman and Pillay 2010 South Africa	Stuttering and self-identity	Open-ended interviews with two females and five males	Theoretical framework: Attitudes, Self- identity and Cognitive theories; Medical Model of Disability	Specific and combined perceptions of Able and Disother were present in the development of self-identity. Stuttering experiences are complicated, as indicated by specific time frames seeing rivalry, combination and mutual presence of forms of self-identity as dual appearance.

Isaacs and	Stuttering in	15 male	Masculinity	Particularly in the
Swartz	relation to	PWS were	informs how male	context of
2020a	masculinity	involved in	PWS are affected	context of communication with
South	mascummty	focus	by their stuttering	possible romantic
Africa			by their stuttering	and sexual partners,
Airica		groups and semi-	Investigation of	as well as
		structured	Investigation of male PWS'	
		interviews		heterosexual males,
		interviews	development and	a stress on being
			management of	situated in
			masculinity was	controlling and
			informed by the	powerful positions
			psychological	was apparent, with
			approach	construction of
				masculinity largely
				ascribing to
				dominant masculine
				norms.
				Furthermore,
				particularly when
				communicating with
				homosexual males,
				female friends and
				relatives, the
				masculine norms
				shaping their day-to-
				day life were
				concurrently
				embraced and
				rebuffed, as part of
				contradictory and
				rival subject
				positions.
				Clearly, it was
				difficult for the
				different variants of
				masculinity to be
				balanced by the male
				PWS. Insufficiency,
				emasculation,
				meekness, humiliation and
				other deleterious
				emotions, as well as
				poor self-confidence
				and self-esteem,
				sometimes resulted
				when they sought to
				reconcile pervading
				masculine norms
				with their stutter

Klompas and Ross 2004 South Africa	The effect on PWS' QoL of their stuttering life experiences	Individual interviews with 16 adult PWS	Effect on QoL of stuttering  Theoretical framework: Medical Model of Disability	Self-perception, self- esteem, work efficacy and education results were all affected by stuttering. Nevertheless, relationships with relatives and career decisions were not affected by stuttering. People have shown negative responses to their stuttering
Nang, Hersh, Milton et al. 2018 Australia	Female PWS' QoL, relationships and self-identity formation in relation to their stutter	Semi- structured interviews with nine female PWS, between 35 and 80 years old.  The Overall Assessment of the Speaker's Experience of Stuttering was also undertaken by the respondents	A minority stuttering group's (females) experiences were illuminated by the research, specifically in relation to how their self-perception and attitudes to their environment are affected by stuttering  Theoretical framework: Possibly Social Capital Theory in relation to power dynamics	The data led to the development of 'gendered sense of self in society' as a main theme. Three wider concepts were connected to this: stuttering management in relation to external assistance experiences, impetuses and internal management; how social bons and interactions such as with romantic partners, associates, co-workers and relatives, were affected by stuttering; self-perceptions of a largely negative character
O'Dwyer, Walsh and	PWS'	Six male PWS	Interpersonal and intrapersonal	There is a relationship between
Leahy	perception of their stutter as	provided	communication,	PWS' personal
2018	an issue in	narrative	social	narratives and the
Ireland	relation to the	accounts.	environment and	broader personal
	influence of	Semi-	broader	narratives that
	narratives		circumstances	develop

	1	T	Γ	T
		structured	influence PWS'	
		interviews	stuttering	
			experiences.	
			Theoretical	
			framework:	
			Interactional	
			Model	
Plexico,	How high-	Two	The stuttering	The coping
Manning	pressure	females ad	experiences of	mechanism of
and	circumstances	seven males	PWS are	avoidance behaviour
Levitt	are managed	participated	influenced by	is adopted by PWS
2009a	through the	in the	their coping	to manage their
	coping	Grounded	mechanisms	stutter, protect
Part1	mechanisms of	Theory		themselves, as well
USA	PWS	research	Theoretical	as those they are
			framework:	communicating with
			Grounded Theory	
Plexico,	Management of	Nine	PWS' stuttering	PWS must learn to
Manning	high-pressure	participants	experiences are	manage their
and	circumstances	involved in	affected by their	stuttering, because it
Levitt	through	the	cognition of	can lead to
2009b	problem-focused	Grounded	stuttering and	considerable stress
	and self-focused	Theory	self-conception	
Part 2	coping strategies	research		
USA	adopted by PWS		Theoretical	
			framework:	
D1 :	**		Grounded Theory	T. C. 1.1
Plexico,	How people	An online	PWS' resilience	It was found that
Erath,	who stutter's	questionnair	and self-	self-acceptance was
Shores and	(PWS)	e was	acceptance inform	connected to
Burrus,	resilience and	completed	their QoL and	resilience. QoL and
2019	self-acceptance	by 47	stuttering	contentment were
USA	influence quality	people who do not	experiences	not mediated by
	of life (QoL)			coping mechanisms, although self-
	and stuttering experience	stutter		
	experience	(PWNS) and 47		acceptance and stuttering's
		PWS.		relationship was
		T W.S.		influenced by
				resilience.
Adriaensens	How self-	76 PWNS	How PWS' self -	The results showed
, Beyers and	confidence is	and 55 PWS	confidence is	that self-confidence
Struyf,	affected by	completed	affected by	of teenagers was
2015	stuttering	questionnair	stuttering's	detrimentally
Belgium		es.	affective and	affected by the
			cognitive	intensity of
			dynamics	stuttering. The effect
			-	on self-confidence of
				stuttering's intensity

		1		
				was significantly moderated by detrimental communication perspectives and maladaptive perfectionism
Erickson and Block, 2013 Australia	How teenagers and their relatives are affected by stuttering in terms of communication and social dynamics.	36 teenagers and relatives of the PWS completed questionnair es.	The social and psychological dynamics of individuals' lives are impacted by stuttering. Theoretical framework: Medical Model of Disability	The results showed that evasion of bullying, intensified anxiety regarding communication, as well as lower than average self-perceptions of communication proficiency, all characterised the PWS. Challenges with handling the irritations of their children, family problems, and significant amounts of emotional pressure were reported by the teenage PWS' relatives.
Hayhow et al. 2002 UK	PWS' perceptions of stuttering's impact, therapeutic interventions, as well as their ambitions	332 participants completed a questionnair e.	PWS' lives are affected by stuttering; improved experiences will result from adopting coping mechanisms and seeking interventions.	Work and education were significantly affected by stuttering, with social effects being lower. No direct explanation was provided concerning benefits of speech and language therapy, although it was identified as useful. Altering therapy in relation to specific personal requirements was identified as important

Kawai,	Children who	80 CWS	Communication	Compared with
Healey,	stutter's (CWS)	completed	perspective and	PWNS, markedly
Nagasawa	communication	the	stuttering	greater pessimism in
and	perspectives	Communica	experiences'	communication
Vanryckegh		tion	connection	perspectives was
em, 2012		Attitude	Theoretical	identified among
Japan		Test-	framework:	CWS
		Revised	Attitudes Theory	
		(CAT-R).		

# Appendix B: Studies Concerning Public Attitudes Relating to Stuttering

Studies con	Studies concerning public attitudes relating to stuttering carried out in western countries							
Study and location	Focus	Research Method Quantitative methods were adopted in the majority of extant studies, providing a basis for social theories, namely regarding how PWS are affected by public attitudes.	Results					
Glover, St. Louis, Weidner (2019) USA	Comparison of attitudes relating to stuttering among adults and children.	The adult and child variants of the Public Opinion Survey of Human Attributes-Stuttering (POSHA-S/Child and POSHA-S) were completed by parents and children at an elementary school in rural Appalachia, as well as other parent-child couplets in the region. Preschool, kindergarten and grades 1 to 5 were the seven grades of children covered.	Compared with their parents, far more negative attitudes relating to stuttering were expressed by the young children, as previous studies evidenced. More affirmative attitudes gradually emerged until children reached 5 <sup>th</sup> grade. For each of the seven grades, similar attitudes towards stuttering were held by parents.					
Walden, Lesner, (2018) USA	Overt and tacit attitudes regarding stuttering among non-stutterers.	Implicit attitudes among the participants were assessed using the Implicit Association Test. This analysed the level of correlation between negative and positive evaluative words, as well as fluent and stuttered speech. Attitudes relating to PWS and non-PWS among the respondents were measured through explicit attitude scales that were selfcompleted by the respondents. Furthermore, a questionnaire relating to PWS' life experiences, as well as measures of social	The presence of a deleterious stuttering stereotype was apparent from the findings. PWS were viewed with direct and tacit negative attitudes by the respondents. Social desirability scores were an important predictor of direct attitudes, although not tacit attitudes, relating to PWS. Furthermore, tacit although not direct attitudes relating to stuttering were significantly correlated to familiarity.					

		desirability, were filled in by the respondents.	
Kumar &Varghese, 2018 India	Analysis of attitudes and understandin g among educators relating to children who stutter at primary school.	Questionnaire distributed to 70 educators.	A mean rating of 63.16% was achieved for the questions relating to educators' awareness of stuttering. 55.7% was the rating achieved for educators' attitude, while educators' opinions of learners' engagement with children who stutter had a rating of 48.5%.
Boyle, 2017 United States	Stigma among the population. Development of an anti- stigma initiative based on analysing public attitudes.	An online questionnaire was filled in by 310 adults, which focused on analysing attitudes relating to PWS as well as stuttering knowledge. Indirect questions considered perceptions of public opinion, while direct questions considered personal perspectives.	PWS' proficiency in carrying out certain work roles, as well as their confidence, were perceived negatively by certain adults.
Valente, St. Louis, Leahy, Hall, Jesus, 2017 Portugal	Assessing the Portuguese public's attitudes towards stuttering.	POSHA-S with 311 adult participants.	Broadly, the results fell in the mean range.
Weidner, St. Louis, Nakisci, Ozdemir, 2017 USA and Turkey	Contrasting the attitudes of US and Turkish preschoolers who do not stutter in relation to stuttering.	POSHA-S with 132 Turkish and 28 US non-stutterers.	There were striking parallels in the Turkish and US children's attitudes. Children who stutter's potential was perceived generally more positively, while their character and qualities were generally perceived with greater negativity.
St. Louis et al., 2016 European countries	Various European nations' public attitudes concerning stuttering.	POSHA-S with 1111 adult participants involved in eight specific studies.	There were striking parallels between the Norway, Italy, as well as Bosnia and Herzegovina samples of adults in terms of attitudes. However, there were rather marked variations across the five countries with regards to attitudes. The different

	1	T	
			country or regions' rank order was not estimated through the POSHA-S based on the demographic factors. In contrast with the global database for POSHA-s, certain countries such as Norway and Sweden has more affirmative attitudes than the mean, while others
			were less affirmative than
(41.1	A	460	the mean, such as Italy.
(Abrahams et al., 2016) South Africa	Attitudes among South African school educators.	469 respondents involved in POSHA-S.	The capabilities of stutters were generally perceived positively, although stuttering's causes and stereotypes regarding character continued to be present. In contrast with the existing POSHA-s database, there marginally more affirmative attitudes among the sample from South Africa.
Arnold & Li,	The	The apparently unconnected	Responses to PWS in
2016 USA	correlation of beliefs and responses to stuttering.	regression (SUR) method, involving 2206 people living in the US.	terms of emotion and behaviour may be affected positively by knowing a PWS and holding affirmative opinions of them.
(Koutsodimitro	Final-year	Semi-structured interviews	PWS were perceived
poulos et al., 2016) Australia	speech pathology students' perspectives and attitudes relating to PWS in Australia.	and POSHA-S in a mixed-method research.	positively by the students.
Adriaensens	Perspectives and attitudes	Semi-structured interview method.	Educators should discuss with their students who
and Struyfa 2016	relating to stuttering	method.	stutter any issues that arise and how they might
Flanders	among		act in response to
(Belgium)	educators, as well as the degree to		stuttering, even if a person who stutters does not think they want to discuss
1	which their		it, or an educator believes

	1	T	
(St Louis et al., 2014)	responses to learners' stuttering are affected by these perspectives and attitudes.  Comparison of Puerto Rican and Norwegian public attitudes regarding stuttering versus cluttering, as well as participants' ability to identify these fluency disorders among individuals.	The amended POSHA-S and POSHA-Cl versions, concerned with stuttering and cluttering respectively, were used to assess attitudes of three Puerto Rican and three Norwegian adults. Additionally, adults or children with stuttering, cluttering or both disorders who the respondents knew personally were asked about.	they are acting appropriately. Accordingly, a student might consider the educator to be more approachable and able to acknowledge their impediment.  For each country and questionnaire, whether stuttering and cluttering combined or solely cluttering, the ratings did not impact on attitudes regarding cluttering.  Cluttering was perceived with marginally less positivity, yet attitudes to both were fairly consistent. In contrast with attitudes in Puerto Rico, affirmative attitudes were more broadly seen among Norwegians concerning cluttering and stuttering. Marginally more than a single fluency disorder was noticed by the respondents on average, with cluttering identified less often than stuttering, while being
Lee, 2014 Korea	Attitudes relating to stuttering among speech language pathologists (SLPs) in Korea.	Assessment of 70 undergraduates studying to become SLPs, as well as 37 qualified SLPs in Korea. The amended Clinician Attitudes Toward Stuttering (CATS) inventory was filled in by each respondent.	Undergraduate and professional SLPs' stuttering attitudes were affected variedly by educational and clinical experience. During clinical activities, undergraduates and SLPs may suffer low self-confidence, despite possessing relevant comprehension of

			particular stuttering aspects.
St. Louis, Przepiorka, Beste- Guldborg, Williams, Blachnio, Guendouzi, Reichel,Ware, 2014  USA and Poland	Determination of course-focused training, as well as how SLP learners' attitudes relating to stuttering are influenced by cultural variables, were focused on.	The POSHA-S was used with eight convenience samples from Polish and US universities, comprising 50 learners each.	In each country, compared with non-SLP learners, positive attitudes were stronger among SLP learners.
Przepiórka, Błachnio, St. Louis, & Wozniak, 2013; Poland	Assess the Polish public's attitudes relating to stuttering.	POSHA-S with 268 participants, with an age range of 15-60 years and mean age of 29.	Existing POSHA-S mean results were broadly analogous with the attitudes relating to PWS expressed by the Polish participants.
St. Louis, 2012 USA	Variations in the population's attitudes among women and men in relation to stuttering.	POSHA-S with 50 women and 50 men, none of whom stuttered or were speech disorder experts.	Women and men had highly analogous public attitudes.
De Britto Pereira, Rossi, Van Borsel, 2008 Brazil	Analysis in Rio de Janeiro, Brazil, of understandin g and awareness of stuttering among the public.	A questionnaire with 606 participants invited on the street.	Particular dynamics of stuttering seem to be poorly understood. Educational attainment, age and gender subsets seem to have varying levels of understanding.
Hertsberg & Zebrowski, (2016)	Non-PWS and children who stutter's self- understandin g of social acceptance	Pictorial Scale of Perceived Competence and Social Acceptance.	Level of social acceptance and proficiency among young children did not vary in terms of self- understanding.

	and proficiency.		
St. Louis, Przepiorka, Beste- Guldborg, Williams, Blachnio, Guendouzi, Reichel, Ware, (2014) USA	SLP learners' attitudes relating to stuttering.	The POSHA-S was used with eight convenience samples from Polish and US universities, comprising 50 learners each.	In each country, compared with non-SLP learners, positive attitudes were stronger among SLP learners. In the USA, undergraduate learners' attitudes were more negative than graduate learners, with non-SLP learners having a more pronounced negative attitude than SLP students.  Attitudes among American non-SLP students were analogous with those expressed by learners of Native American background. Compared with the US learners, more negative attitudes were held by the Polish learners.
Weidner, St. Louis, &	Transform attitudes	POSHA-S.	General attitudes relating
Glover, (2018)	relating to		to stuttering among children saw statistically
310 (21, (2010)	stuttering		significant enhancements.
	among		
	children.		
Stuttering-rel	ated attitudes a	mong Arab populations. Eacl	h study is of an empirical
G. 1		nature.	<b></b>
Study and	Focus	Research Method	Results
location	Daliafa	100 manages with a 1.111 C	A look of and a set as disc
(Safwat &	Beliefs,	100 parents with a child of	A lack of understanding
Sheikhany,	understanding	pre-school or school age	around stuttering's
2014)	,	who stuttered responded to a	character was expressed

#### Egypt questionnaire. The parents by the respondents, despite their acquaintance consciousness were quite young, between , perceptions 26.8 and 44.3 years of age, and attitudes with the condition. PWS with 44% being males and and stuttering as a relating to condition were perceived 56% females. stuttering among Arab negatively by certain parents. parents. Attitudes towards and understanding of stuttering were found to be significantly correlated

			with educational attainment, as well as gender to a certain degree.
(F. A. Abdalla & St. Louis, 2012) Kuwait.	Attitudes relating to stuttering among Arab parents. A POSHA-S amended Arabic variant was adopted.	209 Kuwaiti pre-service as well as 260 in-service public-school educators completed the POSHA-S.	Most of the educators expressed stereotypes relating to PWS and had incorrect knowledge of the disorder, which was the principal research result. This was despite numerous educators being familiar with PWS and communicating with them respectfully.
Al-Khaledi, Lincoln, McCabe, Packman, Alshatti, 2009	Stuttering- related beliefs, understanding and attitudes among Arab parents.	424 Kuwaiti Arab parents completed the POSHA-S.	Culture has an impact on stuttering attitudes. The majority of Kuwaitis seem to be acquainted with stuttering. However, there were shortcomings in understanding of it.
Abdalla & St. Louis, 2014 Kuwait	Altering attitudes relating to stuttering among Kuwaiti preservice students and in-service public-school educators, through presenting an instructional documentary.	POSHA-S with 90 respondents.	The findings evidenced that through presenting an instructional documentary, attitudes relating to PWS among pre-service students could be improved.
Al-Shdifat, Maayah, Mayo, & Louis, 2018 Jordan	Existing POSHA-S database information on international students was compared with Jordan University Communicati on Sciences	The Arabic POSHA-S variant was completed by 179 learners.	Compared with the Jordanian public, attitudes among CSD students were more affirmative.  Nevertheless, in contrast with existing POSHA-S database information regarding SLP learners in other areas, less affirmative attitudes were held by Jordanian learners.

and Disorders	
(CSD)	
students'	
attitudes	
relating to	
stuttering.	

# Appendix C: CASP Evaluation of Qualitative Studies (Lived Experience of Stuttering)

Author(s)	1	2	3	4	5	6	7	8	9	10	
and Year	_	_		-							
Beilby et al.	Yes	Yes	Yes	Can't	Yes	No (2)	Yes	Yes	Yes	Yes	
(2013)				tell (1)							
(mixed											
methods)											
	sion cr	riteria 1	for the	participa	nts wer	e explaii	ned, but i	nadequate	e		
(1) Inclusion criteria for the participants were explained, but inadequate clarification of the recruitment process.											
				-		nd subje	cts' assoc	ciation on	the		
	(2) No direct explanation of the researcher and subjects' association on the qualitative part of the study.										
Bricker-	Yes	Yes	Yes	Yes	Yes	No (1)	Yes	Yes	Yes	Yes	
Katz,							(But)				
Lincoln,							(2)				
Cumming,											
(2013)											
(1) No di	rect ex	kplanat	tion o	f the resea	rcher a	nd subje	cts' assoc	ciation.			
(2) 'This	study	was ap	prove	ed by the H	Human	Ethics C	Committe	e of the U	Inivers	ity	
of Syc	dney'.	Yet m	ore in	formation	neede	d in term	s of conf	identialit	y and	-	
inforn	ned co	onsent	(what	included i	in the p	articipar	nts' infor	mation sh	eet).		
Bricker-	Yes	Yes	Yes	Yes	Yes	No (1)	Yes	Yes	Yes	Yes	
Katz,							(But)				
Lincoln,							(2)				
McCabe,											
(2010)											
				f the resea							
				ed by the H						ity	
				mation nee				•			
				luded in th	1 1	1 -	ı	· · · · · ·		I	
Butler	Yes	Yes	Yes	Yes	Yes	Can't	Yes	Yes	Yes	Yes	
(2013a)						tell (1)					
				f the resear					1	l	
Carter,	Yes	Yes	Yes	Can't	Yes	Can't	Yes	Yes	Yes	Yes	
Breen, &				Tell (1)		Tell (2)					
Beilby,											
(2019).											
	_			dence of t	_		might ha	ve been a	ffected	d by	
		_		d therapy i	n some	form.					
(2) No pr						NO (1)	- ·	1	T		
Carter,	Yes	Yes	Yes	Yes	Yes	NO (1)	Can't	Yes	Yes	Yes	
Breen,							tell (2)				
Yaruss,											
Beilby,											
2017											
(Mixed											
study)											

` /		1		f the researing ethics.						
Crichton-	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Smith	103	103	103	103	103	103	103	103	103	103
(2002)										
(2002)										
Daniels,	Yes	Yes	Yes	Yes	Yes	Yes	Can't	Yes	Yes	Yes
Gabel, &	108	168	105	108	108	168	Tell (1)	108	108	103
Hughes,							Ten			
(2012)										
, ,	mbian		hothor	e othical av	thorico	tion was	hoina ro	formed to	in tha	
				ethical au						
				ing Green	State C	miversit	y s num	an Subjec	is Kev	iew
	Yes		Yes	research.	Yes	Yes	Can't	Yes	Yes	Yes
Daniels,	168	Test	168	1 68	168	168	Tell (1)	168	168	1 68
Hagstrom,							TCII			
& Gabel,										
(2006)	4 :			-41-1	C14	:-1:4	1	4 - : 41	4	
(1) No inform			_			-		_		
	•			American						
_			ormai	tion regard	iing the	rational	e or expi	oring the	ir iden	tities
may be re			<b>3</b> 7	X/	37	37	<b>X</b> 7	C 24	37	*7
Ellis, &	Yes	Yes	Yes	Yes (But (1))	Yes	Yes	Yes (but (2))	Can't Tell (3)	Yes	Yes
Hartlep,				(But '')			(but '')	Ten		
(2017)		1 .	1 1	41 1	<u>, ·                                     </u>	1 11	1'			
		-		ether adop	_					1 '1
-			_	other resp	onden	ts for the	study—	was effec	tive, w	hile
		limited	-	•						
	_			n was prov		-		-		
				ho stutter						ıld
				greater de <sub>l</sub>		h as who	ether the	rationale	of the	
		-		to respond						
		sparen	t data	analysis w	as prov	vided, ye	et rugosit	y was ins	ufficie	ntly
explo		1			1	1		Т	Г	ı
Isaacs, &	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Swartz,										
(2020a)										
		T			T	1		T	ı	ı
Klompas	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
&Ross										
(2004)										
Nang,	Yes	Yes	Yes	Yes	Yes	Can't	Yes	Yes	Yes	Yes
Hersh,						Tell (1)				
Milton, &										
Lau,										
(2018).										
(1) No pr	ovisio	n of in	forma	tion.						
Kathard et	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
al. (2010)										

O'Dwyer,	Yes	Yes	Yes	Yes	Yes	Yes	Can't	Yes	Yes	Yes
Walsh, &							Tell (1)			
Leahy										
(2018)										
(1) No pe	rtinen	t ethic	s info	rmation co	ould be	found.				
Plexico,	Yes	Yes	Yes	Yes	Yes	Can't'	Can't	Yes	Yes	Yes
Manning,						tell (1)	tell (2)			
Levitt,										
(2009a) and										
(2009b)										

<sup>(1)</sup> Researcher subjectivity was covered to a certain extent, although the respondents and the researcher's prior relationship was not discussed. Given that the researchers had worked with the respondents in two previous investigations, there was a particular requirement to explain any relationship.

<sup>(2)</sup> No discussion of ethics, confidentiality or consent seemed to be provided.

# **Appendix D: Example of Life History Analysis**

The structure of Mohammed's life story	The structure of Mohammed's life		
as told by himself	history, in chronological order from t past		
	to present		
<ul> <li>Life story begins from the age of 7.</li> <li>Aged 7, Mohammed knew about his speech problem due to his peers making fun of him.</li> <li>Because of his negative social interactions at school and during family gatherings, Mohammed started avoidance behaviour during childhood.</li> </ul>	- Age 7 is when Mohammed began comprehending his stutter, despite his stuttering potentially having started before 7 years of age. Of course, Mohammed had life experiences prior to 7 years of age, yet he opted to start his life story then because that is when his story with stuttering began. Subsequently, this may indicate that Mohammed locates his stutter as a central aspect of his life.		
<ul> <li>From school age until the present, Mohammed has thought about others' perceptions of him.</li> <li>From the past until now, Mohammed's self-concept has been affected by his previous social interactions.</li> <li>Mohammed focuses on elementary and secondary school because that is where he suffered, being the youngest and only child still living with his old parents and with nobody who could protect him from others' bullying and abuse.  Mohammed did not have anybody with whom he could discuss his social problems while at school.</li> <li>When I asked Mohammed to tell me some of his past stories, he was unable to tell me any stories of what had happened to him during his childhood. This is because Mohammed would cry if he told me these difficult stories, which continue to negatively</li> </ul>	<ul> <li>Mohamed structured his life story chronologically from past to the present.</li> <li>Regardless, the majority of his life story concerned his childhood and previous memories. This may indicate the long-lasting effect of Mohammed's childhood experiences on his perception of his life story.</li> </ul>		

affect him and that he has still	
	76.1
not overcome.  - Afterwards, Mohammed looked back on his negative childhood experience, wondering about and potentially regretting that he did not do anything to defend himself against the children who abused him. Mohammed believes that if he had taken action then his present feelings regarding his childhood t experience may not have posed him as much difficulty as they do now.  - Mohammed's school experience improved when he reached high school, because he was able to develop some self-esteem.  - However, he continued to	<ul> <li>Mohammed did not overcome the pain resulting from his negative experiences.</li> <li>Although his school experience improved once he entered high school, Mohammed concentrated on the negative aspects of his stuttering-related experiences.</li> <li>Focusing on the negative aspects of his childhood may not mean that Mohammed had no positive experiences during his childhood, although it may indicate the long-lasting detrimental effect on him.</li> </ul>
avoid talking to others.	
<ul> <li>Stuttering and job opportunity.</li> <li>Stuttering and avoidance in his workplaces.</li> <li>Mohammed is content with his wife and three children, although they are unaware of his stuttering because he is silent for much of the time.</li> </ul>	- The sole positive aspect of his life is his job and family.
- When I asked Mohammed whether he needed something from his family, he stated that at his age he does not need anything from them.	- Therefore, Mohammed, appears to be influenced by Saudi Arabia's social norms and social power.

# **Appendix E: Interview Transcripts**

https://1drv.ms/b/s!ArLZfkbjlph0kVIMoM7l1wlGsmwR?e=80eVrb

# **Appendix F: Participant Information Sheet and Consent Form**



Researcher:

Name: Reham Bukhari

Phone:

Email: r.s.y.bukhari@pgr.reading.ac.uk

**Supervisors:** 

Name: Naomi Flynn

Email: n.flynn@reading.ac.uk

Name: Cathy Tissot

Email: c.tissot@reading.ac.uk

#### PARTICIPANT INFORMATION SHEET

I am a PhD candidate at the University of Reading, UK. As part of the data collection stage of my dissertation, I am writing to invite you to take part in this research study.

# **Research Project (Title):**

A qualitative exploration of how people who stutter (PWS) perceive their academic and professional lives in relation to their interaction with their social and cultural environment.

# What is the study?

This life-history research aims to explore Saudi stutterers' perceptions of their educational and professional lives, and how they make meanings of the key relationship between their stuttering/social environments and their academic and professional lives, in different stages of their lives. Participants will be given the choice to talk about the different environments they have experienced. The aim is to give stutterers a voice and raise public awareness about stuttering.

#### Why have you been chosen to take part?

You have been chosen because you are a Saudi Arabian citizen with experiences of a stutter and are aged over 18. Thus, your participation is highly valuable for this research, and the data obtained from you will certainly contribute to exploring knowledge about stutterers' experiences stuttering and their concerns regarding their academic and professional lives

# Does I have to take part?

It is completely up to you decide whether or not to take part in the study. Even once you have decided to participate and have signed the information sheet, you can to withdraw your participation at any point during the data collection process, by contacting me, r.s.y.bukhari@pgr.reading.ac.uk

# What will happen if I take part?

You will take part in a life-history interview to discuss and talk/write/draw about topical issues in your life story, including, for example, your social relationship with the people around you, and your educational and professional experience. You will be provided with the interview topics one week in advance of the interview date to allow time to prepare your responses. This interview may take from one to two hours.

After the life-history interviews are conducted, you will have a chance to participate in follow-up interviews, from 30 minutes to one hour to expand on specific topics which were not discussed in depth in the life-history interviews.

All interviews will be recorded and transcribed with your permission. The transcription will be shown to you in order for you to check that you are still happy for its contents to be used. The information gathered will be used by the researcher for data analysis.

You can come to an agreement with the researcher as to when and how you would like the interviews to be conducted. For example, the interview can be conducted via Skype if you are comfortable with a video interview, and, if you prefer, your answers can be written/drawn rather than vocalised.

# What are the risks and benefits of taking part?

It is not anticipated that there will be any disadvantages or risks associated with taking part in this study. Although, there is no direct benefit to the research participants in the first instance, yet the information gathered from this thesis will be used to fill the gap in the research on stutterers' perspectives of their stuttering and its impact on their academic and professional lives.

#### What will happen to the data?

I will ensure that all the data provided will be kept strictly confidential and anonymous. Only the researcher and supervisors will have access to it. The records of this study will be kept private. Participants will be asked to choose a pseudonym and will be referred to by that pseudonym in *all* records. Research records will be stored securely in a locked filing cabinet and on a password-protected computer and only the researcher Reham Bukhari and the Supervisors Dr Naomi Flynn and Professor Cathy Tissot will have access to the records. The results of the study will be presented at national and international conferences, and in written reports and articles. We can send you electronic copies or a short summary of these publications if you wish.

## What happens if I change my mind?

You can change your mind at any time without any repercussions. If you change your mind after data collection has ended, we will discard the data. In addition, you have the right to choose what information you wish to share during the interview process; you can reshape the interview questions, or outright refuse to answer questions.

# What happens if something goes wrong?

In the unlikely case of concern or complaint, you can contact the researcher <a href="r.s.y.bukhari@pgr.reading.ac.uk">r.s.y.bukhari@pgr.reading.ac.uk</a> Or Dr Naomi Flynn and Professor Cathy Tissot (supervisors), University of Reading; <a href="n.flynn@reading.ac.uk">n.flynn@reading.ac.uk</a> <a href="c.tissot@reading.ac.uk">c.tissot@reading.ac.uk</a>

## Where can I get support if I get upset as a result of the interview?

This public government organisation has been established to support people who need the advice to deal with personal issues. "Ershad Al-Riyadh". Freefone:

Sunday-Thursday 6pm-9pm, for men and women; 9am-12pm for women only.

# Where can I get more information?

If you would like more information, please contact the researcher Reham Bukhari
Tel: , email: r.s.y.bukhari@pgr.reading.ac.uk

We do hope that you will agree to your participation in the study. If you do, please complete the attached consent form and return it with a 'read-only' copy to my email r.s.y.bukhari@pgr.reading.ac.uk

This project has been reviewed following the procedures of the University Research Ethics Committee and has been given a favourable ethical opinion for conduct. The University has the appropriate insurances in place. Full details are available on request.

Signed: (Researcher) Reham Bukhari

Date: 15/11/2018

**Consent Form** 

Project title:

I have read and had explained to me by Reham Bukhari the Information Sheet relating to this project.

I have had explained to me the purposes of the project and what will be required of me, and any questions have been answered to my satisfaction. I agree to the arrangements described in the Information Sheet in so far as they relate to my participation.

I understand that I will be interviewed and that the interview will be recorded and transcribed.

I understand that my participation is entirely voluntary and that I have the right to withdraw from the project any time, without giving a reason and without repercussions.

I understand that, after the life-history interviews, I may be asked to attend a followingup interview, and I have the right to accept or refuse this invitation as I choose.

I have received a copy of this Consent Form and of the accompanying Information Sheet.

Please tick as appropriate:			
I consent to being interviewed:			_
	yes	no	
I consent to this interview being re	ecorded:		
		Yes	no
Name:			
Signed:			

# طلب المواققة Consent Form

-A	- 1	- 2-
200.00	1 - 40	-

دراسة وجهات نظر الاشخاص الذين جريوا التأثأة حول تجريتهم وكيف اثرت التأثأة في حياتهم بشكل عام و حياتهم الاجتماعية والأكاديمية والمهنية بشكل خاص, بالإضافة الى مدى تأثير الجوانب الثقافية والإجتماعية على تجرية التأثأة.

لقد قرأت وفهمت من خلال رهام يخاري ورقة مطومات المشاركين المتطقة يهذا البحث

رهام يخاري وضحت في الهدف من هذه الدراسة وماهو المطلوب مني وكل استقساراتي تمت الاجابة عليها وتوضيحها و أنا اوافق على كل ما ورد في ورقة معلومات المشاركيين.

أنا افهم ان مشاركتي في هذا البحث مشاركة تطوعية واستطيع رفض المشاركة أو الأنسحاب منها يدون الحاجة الى تيرير ذلك

انا افهم مشاركتي سوف تكون مسجلة صوتها او كتابها ولن يستمع الى صوتي أو مطوماتي الشخصية احد غير رهام يخارى

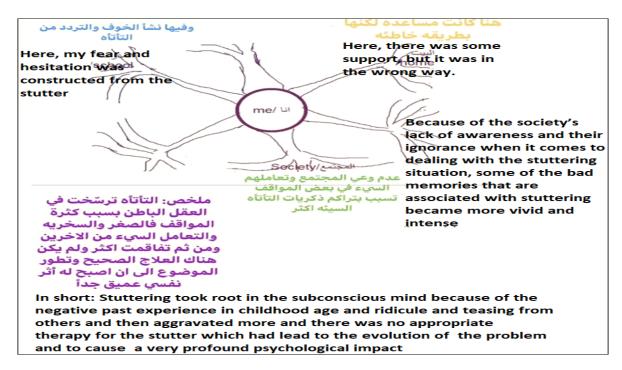
أنا افهم ان مشاركتي سوف تكون سرية لن تكشف اي مطومات عن هويتي ولن تستخدم في أي غرض غير غرض البحث حول تجارب التأثأة

أنا افهم ان بعد هذه المقابلة قد تقوم رهام بخاري بالتواصل معي في وقت لاحق للحصول على معلومات اكثر عن التجرية في التأتياة ولي الحق في القبول أو الرفض

لته حصلت على نسخة من هذه الورقة لأخذ موافقتي وايضا قد اعطيت المعلومات اللازمة حول المشاركة

لو سمحت عُمع صح في المكان المقاسب لك
أنا اواقع على المقابلة تعم ( ) لا ( )
أنا اواقع على تسجيل المقابلة نعم ( ) لا ( )
الاسم المستعار
التوقيع

# **Appendix G: The Participants' Visual Materials**



Ali's Visual Material

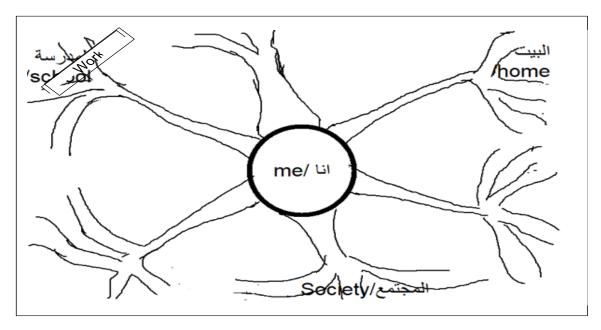
Ali chose this chart, in which he locates himself in the middle between home, school, and society. Ali said that he is impacted by all of the three elements. However, these elements may not be affected by each other. Therefore, when Ali talked about these elements, in the narrative Life-Story, he described them in stages, started from home, then school and lastly society.

He maintained that his family offered him with support when he was a child. However, he interpreted his **family's support** as inappropriate. Ali did not provide details about how his family dealt with him as a child. Therefore, although Ali sees his family support as inappropriate, this is only his interpretation of the support and may not indicate that his family used negative strategies when dealing with Ali's stuttering.

In school, Ali state that he started to create **negative feelings and behaviours** such as fears and hesitation because of the stutter. He explained that negative **social interactions** in school, such as others' adverse reactions and lack of support, made him construct these negative attitudes.

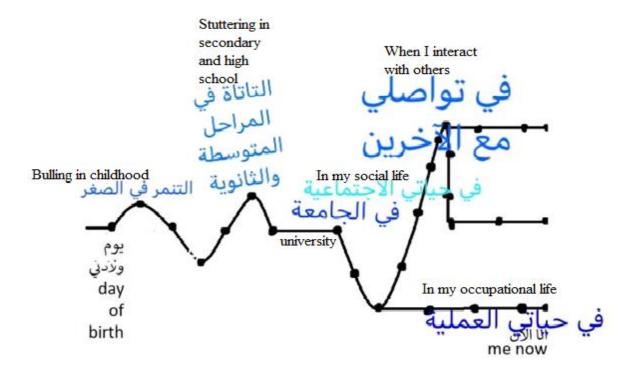
Regarding society, Ali indicates that public **lack of awareness** and their **adverse** reactions to people's stutter in social settings can cause a **long-lasting impact** on people

who stutter. Therefore, it can be seen, from Ali's chart, that society and related factors can play a significant role in shaping people experience of stuttering. Ali added that children's negative experience of social interactions, such as teasing and bullying, can lead to cause the stutter and/ or make it severer. Therefore, Ali indicates the influence of negative social interactions in people's experience of stuttering.



Abu-Abdullah's Visual Material

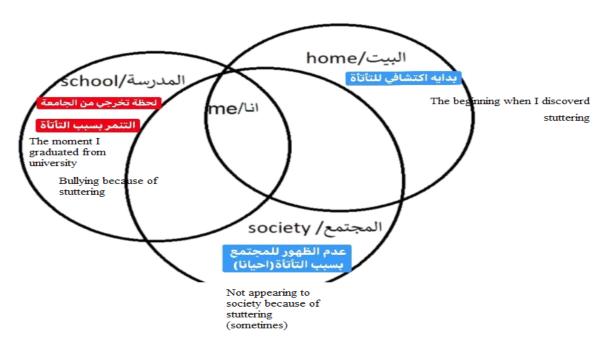
Abu-Abdullah explained that he selected this shape because he considered himself to be situated in the middle of all three elements, namely home, society and work. Accordingly, Abu-Abdullah indicated that his life-story is affected by all three elements. He decided to replace school with work, which is potentially because he did not attend university and opted to work as opposed to studying. Regarding his home life, Abu-Abdullah explained his current contentment with his wife and children. However, in society he experienced many negative responses and reactions from others



## Kholod's Visual Material

Kholod chose to present her Life-Story in the form of a flow chart, explaining her rationale as being because she considered her life experiences to represent something **stable**, particularly in terms of her **job**. Nevertheless, Kholod has faced difficulties during her **social interactions** with others. Kholod's first point made in the chart is that she was mocked and unkindly mimicked during her **adolescence**. Subsequently, she departs from the **stable** line while representing her stuttering experience at both **secondary** school and **university**. Evidently, these educational experiences had a considerable detrimental effect on her, thus explaining the prominence she gives them in the chart.

The final section of the chart presents a trifurcated line; three diverging paths, with each representing a particular **level of difficulty** she has faced. The **lowest** line presents part of her life when she faced no problem, during her **professional life** as a maths teacher. The **middle** line concerns her **social life**, where overall she has faced some challenges. The **uppermost** line relates specifically to her **oral interaction with others**, indeed being the aspect which she considers most problematics.

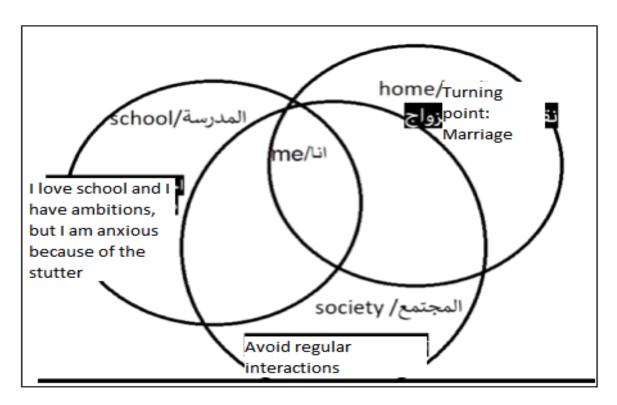


Baraa's Visual Material

Baraa chose to locate himself in the middle between the overlapped circles which represent home, school and society. The relationship between the three elements are overlapped, therefore, all elements are impacted by each other.

He also decided to use colours to highlight the important events that had happened to him in his Life-Story; he explained that, those highlighted in **red are the most significant** and finished stories in his Life-Story, while those highlighted in **blue considered as stories that still negatively impact him.** Therefore, it can be seen that Baraa chose to mention the story of **the beginning of his stuttering** because he indicated that what had happened at that time had shaped his current life; he is still stuttering as a result of the story that happened at the beginning when he discovered his stuttering. In addition, Baraa said that, as a result of being a stutterer he tends to **avoid** engaging in social interactions.

**Educational related achievement** are considered as a significant point in Baraa's Life-Story. The value that Baraa gave to the educational part of his life might have been constructed from his understanding of the social role in his society, in which adults have to achieve a certain level of education in order to work and, in turn, to meet social expectations.



Al-Anood's Visual Material

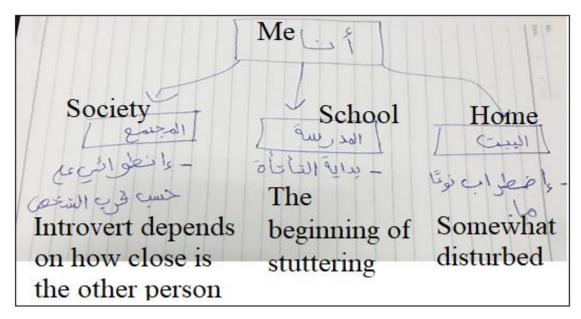
Al-Anood situated herself as central among all of the mind map elements (Figure); she opted to describe every component using a single sentence. Concerning home life, Al-Anood wrote 'turning point: marriage', explaining that prior to getting married, she believed that once she got married she would overcome her stuttering. However, Al-Anood was apprehensive that she would have to explain to her future fiancé that she stutters. Nevertheless, having ultimately got married, she was unable to discuss her stutter with her husband. She added that despite her husband having observed her stuttering, no one understands how she feels. Al-Anood's narrative of her spousal relationship may highlight the role of arranged marriage, which is still pervasive in Saudi society, as well as family support that is provided by husbands.

Concerning education, Al-Anood explained that a conflict exists between her ambitions and her stutter and fears. She related how, when she was a child, she aspired to become a doctor and imagined herself in a high position, although when she returned to reality she felt fearful. Al-Anood indicated that until the present time, her fears of stuttering prevented her from fulfilling her aspirations:

'By the way, I still would like to study a master degree, but my fear of stuttering still prevents me from doing that.'

For society, Al-Anood wrote that she avoids social interactions, clarifying that despite wanting to participate in conversations, she is also reluctant to do so because she is fearful that she will stutter in front of others, both during family gatherings and social contexts. Overall, Al-Anood's visual material presents a form of conflict in the way she perceives her stuttering experience. For example, despite anticipating that her marriage would reduce her stuttering, it did not. Moreover, although she possessed a desire for high academic achievement, her stuttering fears prevented her from doing so. Furthermore, she wants to socialise with others,

yet due to being afraid of possibly stuttering before them, she prefers to evade such communication.

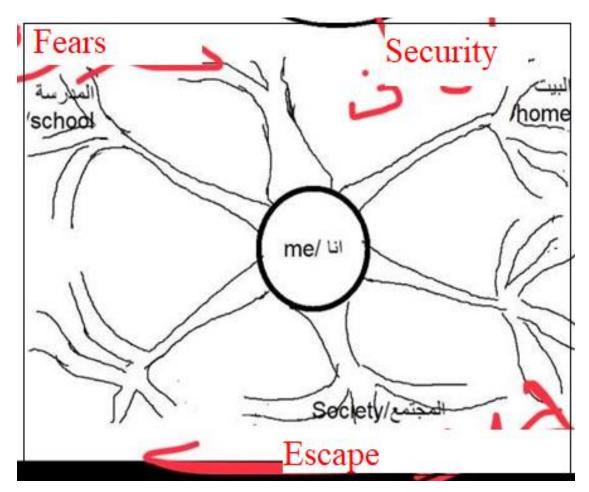


Fahad's Visual Material

Fahad opted to draw his Life-Story on a white sheet of paper, dividing it into three main elements, namely home, school and society. At home, Fahad was posed with certain **challenges and disturbances**, while it was during school that he initially **discovered his stutter**. In society, Fahad found himself being **unsociable**, particularly with people who he was unfamiliar with.

The manner in which Fahad drew his Life-Story indicates how he perceived the three elements from a distance, because he placed himself above these elements and connected to them via unidirectional arrows from the person (him) to each element. Moreover, these elements appear distinct from each other, because he did not link between them with arrows. Accordingly, Fahd may not consider these elements to be overlapping or

interacting. When I asked Fahad about my interpretation of this image, he concurred and added that he wanted to make it simple, in order to focus on these significant **elements that shaped his life-Story with stuttering**.

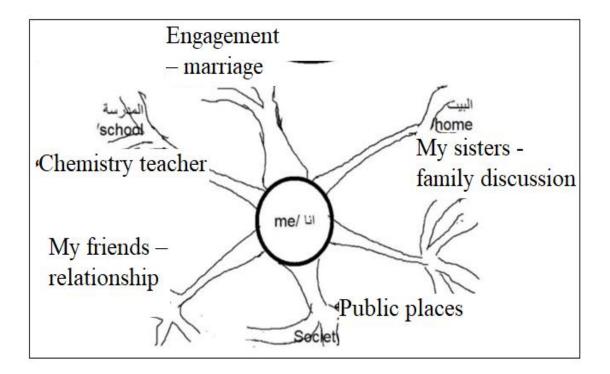


Omer's Visual Material

Omer situated himself as central in the above mind map; he opted to describe each element using a single word. For home he wrote 'security', explaining that since his childhood Omer's family had provided him with a sense of **security and acceptance**. Therefore, he was not fearful of stuttering at home. Regarding school, Omer wrote 'fears', clarifying how his stutter began at school as a consequence of the intimidating situations he had experienced. For society, Omer stipulated that this is the place that he wanted to 'escape' from, stating that in his society there is insufficient awareness as well as negative reactions to his stuttering. Consequently, he wanted to move away from his society. Through assessing the above mind map and the words that Omer wrote, it is apparent that they are very different meanings included. While he felt safe at home, school

was a site where his fear played out. Moreover, whereas his home life saw Omer being accepted, Omer does not want to be a part of his society. Such elements may all have contributed to the **construction of Omer's Life-Story**.

Figure 4.7: Example of Visual Analysis



# Sarah's Visual Material

Sarah described this mind map as reflecting the roots of a tree, with each root connected to a different feeling. Based on the above chart and Sarah's explanation, it is evident that Sarah perceived herself as a tree that has been shaped and affected by her life events, in addition to the feelings stemming from what had happened to her. On the chart's roots, Sarah wrote the significant events that had influenced her life story. At home she felt more negatively affected by her sisters and their comments, while her school life was characterised by negative experiences due to her Chemistry teacher's attitude. Additionally, her friends and relationships informed her life experience. Being in public settings has provided a space which influenced Sarah's cognition regarding her stuttering experience, while her future concerns relate to getting engaged and married, as she remains single.

Note: Sarah opted to concentrate on those events that potentially had a **negative effect** on her stuttering experience. For example, despite Sarah's mother being supportive, as explained to me in the narrative data that Sarah provided, she chose not to highlight this on the chart.