

The experiences of selectively mute adults in education

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Abstract

Background

This study explores the experiences of adults with selective mutism (SM). The motivation for this research stems from a conversation between the author, who has SM, and others living with SM in an online community that discussed the need to allow adults with SM to be heard, especially for those still experiencing SM in higher education. This study describes participants' experiences of living with SM while at school and the levels of support they received. Though much of what made this research possible began with my personal circumstances, it was my experiences working as a narrative therapist suffering with SM, and later as a tutor teaching students facing similar challenges, that convinced me that the stories of people with SM needed to be told.

Method

This research used a qualitative approach informed by an open ended questionnaire about school experiences of adults with SM. Participants data was gathered by means of an online questionnaire that asked them to reflect on their schooling, their experiences with school staff, support services, and their families' reactions to having a family member with SM.

Findings

Participants talked about the effects of SM in terms of social and educational engagement, family experiences, peer and teachers' relationships, lack of information about SM, emotional experience, stigma, and the coping mechanisms they utilised to navigate throughout life. Thematic analysis was used to determine the key themes of participants' narratives, and these informed the development of a Selective Mutism Spectrum (SMS). The following main themes were identified: recognition of diagnosis, educational experiences, emotional experience, family experiences, help seeking, coping mechanisms, and participant recommendations.

Conclusion

The research focused on participants' schooling as a context, as this is often the first place that SM is identified and where students are recognized as not being able to communicate with other students in certain situations. School is usually where most other diagnosed mental health or learning disabilities would receive support. However, participants in the research described a lack of learning support from teachers who had little or no understanding of SM, which in turn meant a lack of access to support services and adequate support practice. The SMS is constructed as part of the demographic information and ideas that came from the participants stories, as a manner in which to practice or identify SM in students in the future.

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**He aha te mea nui o te ao
What is the most important thing in the world?
He tangata, he tangata, he tangata
It is the people, it is the people, it is the people
Maori proverb**

Table of Contents

Acknowledgement.....	ii
Chapter 1: Research Introduction.....	1
1.1. Positioning the researcher.....	2
1.2. Organization of this thesis.....	3
Chapter 2: Literature Review.....	5
2.1. Characteristics of Selective Mutism.....	6
2.2. Diagnosis of Selective Mutism.....	7
2.3. Consequences of Selective Mutism.....	9
2.4. Therapy.....	10
2.5. Children and Adults with Selective Mutism.....	14
2.6. Education.....	17
2.7. Summary.....	23
Chapter 3: Methodology.....	23
3.1. Aim of Study.....	24
3.2. Research Design.....	25
3.3. Participants.....	26
3.4. Data Collection.....	28
3.5. Data Analysis.....	28
3.6. Ethics.....	30
3.7. Cross Cultural Considerations.....	32
Chapter 4: Participant Profiles.....	34
4.1. Demographics.....	34
4.2. Participant Profile: Susan.....	35
4.3. Participant Profile: Taonga.....	35
4.4. Participant Profile: Olivia.....	36
4.5. Participant Profile: Brandy.....	36
4.6. Participant Profile: Emma.....	36
4.7. Participant Profile: Decland.....	36
4.8. Participant Profile: Edna.....	37
Chapter 5: Findings.....	38
5.1. Recognition of diagnosis.....	38
5.2. Educational and Academic.....	41
5.2.1. Peer Experiences and Relationships.....	41
5.2.2. Educational and Academic Experiences	42
5.2.3. Classroom interactions.....	45
5.3. Emotional Experiences.....	46
5.3.1. Sense of Isolation.....	46
5.3.2. Bullying and Stigmatization.....	48
5.3.3. Mental Health Challenges.....	50
5.3.4. Long Lasting Memories.....	51
5.4. Family Experiences.....	52
5.4.1. Lack of Recognition.....	52
5.5. Help Seeking	54
5.5.1. At school.....	54
5.5.2. University.....	56
5.5.3. Support Services.....	51
5.5.4. Other sources of support.....	57
5.6. Coping Mechanisms.....	58

5.6.1. Resilience.....	58
5.6.2. Sports and extracurricular.....	60
5.7. Participant Recommendations.....	60
Chapter 6: Discussion.....	63
6.1. Diagnosis and Identification.....	63
6.2. Education.....	65
6.3. Support Services and Treatment.....	67
6.4. Assumptions and stigma.....	68
6.5. Strengths and limitations of research.....	71
6.6. Selective Mutism Spectrum (SMS).....	73
6.7. Recommendations.....	76
Chapter 7 Conclusion.....	77
7.1. Participant Recommendations.....	78
References.....	80

List of Figures

<i>Fig.1: SMS: Selective Mutism Spectrum.....</i>	<i>75</i>
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Appendices

Appendix 1: Facebook post poster.....	87
Appendix 2: Facebook post message.....	88
Appendix 3: Facebook response to interest.....	89
Appendix 4: Participants information sheet.....	90
Appendix 5: Questionnaire.....	96
Appendix 6: Ethics Approval Letter.....	104

Chapter 1: Introduction

The purpose of this thesis was to explore the experiences of adults who have lived with selective mutism (SM) throughout their lives, especially in relation to their schooling and access to support services. This chapter begins by briefly explaining SM, its background, the research methods adopted for this study, and how the research results were analysed.

Selective mutism is characterized by a consistent failure to speak in social situations where there is an expectation to speak, even though the person speaks in other social situations (Chavira, Shipon-Blum, Hitchcock, Cohan, & Stein, 2007). The failure to speak can have significant consequences for achievement in academic or occupational settings or otherwise interfere with 'normal' social communication (American Psychiatric Association [APA], 2013). Selective mutism affects 0.2 to 2.0% of children, impacts boys and girls equally, and begins typically during preschool and early school-age years (Vecchio & Kearney, 2009). Selective mutism is often first realised when children attend playgroups, kindergarten or school.

This research aimed to explore the experiences of the participants using qualitative narratives of adults with SM retrospectively writing about what it was like at school for them, and whether they thought more could have been done in terms of their personal and educational support. Participants were asked to reflect on their schooling, experiences with learning support, other support services and their families' reactions to having a family member with SM. This research study differs from most existing SM studies by investigating SM from the perspective of adults who have lived with it from a young age; most previous studies have focused on common development issues in childhood.

Choosing education as a context for this research allowed participants' experiences to be specific on the details of their education and related aspects of their lives such as family, support networks and/or treatments they may have encountered. The education setting was a rich part of the experiences of the participants and is the one which integrates both cultural and social experiences (Clarke & Wallace, 2015). Participants in this research and other research previously done by Clarke and Wallace (2015) talked about the challenges they

had faced and the potential of issues the current generation may face. Educational contexts are often where SM first presents and is informally identified by peers and teachers, and as the participants described, it is a key context where changes can be made to manage it. Students with SM are recognized as not being able to communicate in the same way as other students do, and it is usually during the school years when most other students with underlying mental health or learning disabilities would receive support or help (Trainor, 2016).

1.1. Positioning the researcher

My motivation for conducting research that aims to improve our understanding of individuals who have lived with the effects of SM for most of their lives stems from my own experiences as someone with SM. By communicating with my own SM community, other teachers, counsellors and medical professionals, I was able to identify that SM did not affect everyone the same way, and that many professionals wanted more information. Those affected by SM are not limited to one culture or one part of the world. The only common factor is often the feeling of not receiving appropriate support as well as the lack of knowledge around the condition. These were aspects that I was mulling over in my mind when I met with my supervisors to talk about this research topic for the first time. I wanted to be part of people with SM telling their stories and being heard as a researcher with 'insider knowledge' of SM. This included being reflective of possible themes and stories that may be similar to my own experiences of SM and school, and how to remain objective while identifying with participants.

As I advanced in my professional life as a narrative therapist and educator, it became more apparent how much SM affected not only me but also a number of my clients and students. Our stories of these affects often being similar and also sometimes being complex, while for some it was simpler. By connecting with others with SM around the world through the internet, it became clear that these people wanted to tell their stories and wanted their voices to be heard. The stories of the participants in this research speak about the stigmas, the challenges, and the resilience it took to get to where they are today. As a therapist, I came across a lack of understanding among my colleagues, which became clearer as I stepped into an education setting as a tutor. Much like many of the participants,

I grew up never being identified as someone who was living with SM, and I felt stigmatized and defined by people's ideas about what was normal development for my gender and age.

1.2. Organization of this thesis

Chapter 1: This chapter introduces the research, and background to the research, and outlines the structure of the thesis.

Chapter 2: This chapter introduces and reviews the existing literature on SM and education while also introducing further research and theory that relates to the other aspects of education. The literature review covers the topics of SM, life and relationships, critical theory, education and therapies or support services, and a discussion on psychology and polyvagal theory.

Chapter 3: This chapter describes the methods used in this research and why the qualitative approach was adopted, how participants were recruited, and the guidelines for accepting participants. It also includes a discussion about ethics and cross-cultural considerations. The chapter ends by explaining how the collected data were analysed.

Chapter 4: In this chapter participant's data are introduced by showing the demographic data, and making a short introduction of the participants with their pseudonym names.

Chapter 5: This chapter describes the main themes of the findings determined by thematic analysis and distinguishes different ideas and points of view expressed by the participants. The following main themes were identified: recognition of diagnosis, educational experiences, emotional experience, family experiences, help seeking, coping mechanisms, and participant recommendations.

Chapter 6: This chapter discusses the main themes identified in Chapter 5 in relation to the existing literature, and includes consideration of the strengths and limitations of this research. This chapter also explores diagnosis and identification, education, support services and treatment, assumptions and stigma, and the Selective Mutism Spectrum (SMS).

Chapter 7: This chapter concludes the thesis with a summary of the findings while also including the recommendations made by the participants.

The following chapter presents the literature review conducted for this research.

Chapter 2: Literature review

This research explored the educational experiences of adults who have lived with SM from a young age. This chapter presents a review of the existing literature on the topic of adults with SM in education, extending across different disciplines that use terms and concepts in different contexts. The review provides historical background to SM also introduces educational theories such as critical theory aligned with best practice to support students with SM, as well as providing a description of treatment options, including some neurobiological theories that can be potentially used in the possible identification of SM functioning.

The aim of this review was to survey the existing approaches to researching SM in education in order to achieve deeper understanding of the topic. This included ideas derived from the various beliefs of those with SM about the nature of SM (Lundman & Graneheim, 2004). Internet searches were performed on Google Scholar and journal databases, and the Whitireia library catalogue was also searched, resulting in a mixture of online and hard-copy articles and books.

Searches were conducted using the following keywords: 'selective mutism', 'selective mutism in education', 'education paradigms', 'therapeutic intervention for selective mutism', 'critical theory', 'critical approach', and 'transformative learning'. The only restrictions imposed were that the literature had to have been published between 2009 and 2018 to ensure academic sources were recent and had to be in English. Once other disciplines such as therapy and education were added to medical articles, the number of articles found came to around 50, and all were read carefully to establish their relevance. Articles came from many locations including the United States, United Kingdom, Australia, New Zealand, Philippines, China, Mexico, Germany and Italy. Ultimately, a total of 45 sources were determined to be sufficiently relevant to this research.

The literature found in the topic has been divided into seven different themes relate to SM and these include the characteristics of SM, diagnosis of SM, the consequences of SM, therapy, children and adults with SM and education which includes critical engagement and transformational learning.

2.1. Characteristics of Selective mutism

Historically, SM was first identified in 1877 by Adolf Kussmaul, who termed the condition 'aphasia voluntaria'. It was later named 'elective mutism', which reflected the belief that people with the condition were actively choosing not to speak in certain situations. This name was kept in the World Health Organization's (2016) *International Classification of Disease*, until it was changed to 'selective mutism' in a subsequent revision of the Diagnostic and Statistical Manual (DSM) by the American Psychological Society, thus emphasizing the situational nature of SM and the recognition that individuals with SM are not wilfully refusing to speak (Cohan, Chavira, & Stein, 2006).

There is limited scientific information, for example, about the natural causes of SM. Most studies suggest that even though mutism may frequently remit over time, the rate of talking behaviour remains lower than average for an individual living with SM (Chavira et al., 2007). Selective mutism is less common than other psychological disorders and can be associated with significant diminishing capabilities that last more than a month and is not affected by language barriers or any other developmental disorders (Chavira et al., 2007).

In a social anxiety disorder like SM, the person is fearful, anxious or avoidant of certain social interactions and situations that involve the possibility of being scrutinized (American Psychiatric Association, 2013). This could include meeting unfamiliar people or situations where the person may be observed eating and drinking, or situations where the person performs in front of others. The cognitive ideation is that of being negatively evaluated by others, being embarrassed, humiliated, and rejected or even offending others (APA, 2013).

Sutton and Forrester (2016) described some of the subjective experiences of people with SM. They stated that many people with SM have thoughts about acting differently in certain situations before they even start trying to speak, and also that at times a person can come across as cold or distant, finding themselves very sensitive to others, sensitive to themselves, and always self-conscious of everyone and everything in a space. Sutton and Forrester (2016) referred to how a person with SM may feel like their body movements can expose their anxieties,

which shows that SM can affect body language. They might hide their true emotions in a trigger situation by continuously smiling or keeping a fixed facial expression regardless of how they are truly feeling. These authors further state that often the triggers for SM have more to do with other people in certain situations, and certain aspects of life in which they feel the need to have some management over. For instance, the minute someone with SM has to sit with someone who keeps saying or expecting them to change or act a specific way, symptoms can become more prevalent. It may be assumed by others that someone who lives with SM chooses to not speak or to have control over a situation by not speaking, when it is in fact triggered by certain people in a situation, or even certain social situations which become more difficult to manage when they feel under pressure to behave in a specific manner (Sutton & Forrester, 2016).

Sutton and Forrester (2016) also argue that a person living with SM experiences having their voice trapped in their own mind, with some reporting their throat is almost physically locked when put in a stressful position in which they are expected to speak, and want to speak, but cannot. These experiences are not always realized by the sufferer's family since a person with SM may talk at home but not always at school. Selective mutism could feel ashamed and try to keep their condition secret and not tell others about their situation (Sutton & Forrester, 2016).

A few epidemiological studies have been conducted on SM that help us to estimate its prevalence based on larger samples from national or international studies. Studies utilizing clinically referred samples indicate that females are more affected than boys (Cohan et al., 2006). These authors found that SM in children typically presents in some form prior to school entry, but will become more obvious on starting school (Cohan et al., 2006).

2.2. Diagnosis of Selective Mutism

Selective mutism can be found under 'Anxiety Disorders' in the *Diagnostic and Statistical Manual, Fifth Edition* (DSM V), which is the standard manual used to diagnose mental disorders (APA, 2013). Anxiety disorders include disorders that share features of excessive fear, anxiety, and other related behavioural

disruptions (APA, 2013). The SM diagnostic criterion, as noted above, is considered to be a consistent failure to speak in specific social situations in which there is an expectation for speaking, despite speaking in other situations (APA, 2013). Included in this criterion is whether SM disturbs and interferes with education, occupational achievement, or social communication (APA, 2013). A diagnosis of SM will only be considered if the characteristics persist for the duration of at least one month, which is not limited to the first month of school (APA, 2013). Selective mutism will be considered if the occurrence of the characteristics is not better explained by a communication disorder and does not occur exclusively during the course of diagnosing autism spectrum disorder, schizophrenia, or another psychotic disorder (APA, 2013).

Other theories derived from psychoanalysis have tried to explain the development of SM, but limited consensus has been found regarding its cause. However, early psychodynamic and family systems theories have viewed SM as a result of exposure to trauma, unresolved intrapsychic conflicts, and controlling and/or oppositional behaviour (Cohan et al., 2006). However, over the last few decades psychodynamic conceptualization has decreased significantly with SM seen as more explainable by anxiety-related theories (Cohan et al., 2006).

Wong (2010) suggests that the prevalence of SM is believed to range from 0.47% to 0.76% of the population based on previously pooled case studies from different locations such as Western Europe, the United States, and Israel. Previously prevalence was reported as much lower, at 0.03% to 0.2% across several epidemiological and cross-cultural studies. The wide range reflects the lack of consistency and agreement in establishing diagnosis from previous chart reviews and the infrequent use of standardized assessments, which has led to no new assessment tools being created. Wong (2010) concluded that researchers seem to place less attention on this area due to the low occurrences suggested by the literature.

The American Psychological Association (2013) suggests that individuals with a social anxiety disorder such as SM, can overestimate the danger in some situations and/or take steps to avoid those situations (APA, 2013). The decision of the severity and diagnosis of this condition is judged by a mental health clinician. Cultural contexts are also be taken into account, including how they might affect

someone living with the effects of such a disorder. Many anxiety and social anxiety disorders develop in childhood and tend to persist if not treated (APA, 2013).

There are limitations to establishing the prevalence of SM due to the lack of a comprehensive and uniform theory explaining the aetiology or addressing the appropriate, assessment and treatment of SM. Viana, Biedel and Rabian (2009) state that studies relying on chart reviews for diagnosis and standardized structured assessments are rare as there have been very few steps taken by researchers to understand SM from a developmentally psychopathology perspective, despite compelling clinical evidence revealing a complex and multidetermined aetiology.

2.3. Consequences of Selective Mutism

Selective mutism can become a situational anxiety disorder of communication affecting around one in 150 younger children during their early lives (Sutton & Forrester, 2016). Though the literature shows a long history of SM studies and focuses on how it can develop, especially while in school, there are also some large gaps within the existing research.

Previous literature suggests that speech interference affects education, and shows that the occupational achievement or social communications for someone who has lived with SM for a prolonged time is significant (Cohan et al., 2006). Associated features of SM also identified that can impact occupational achievement and social communications can include excessive shyness, fear of social embarrassment, social isolation and withdrawal, clinging, compulsive traits, negativism and temper tantrums, particularly at home (Cohan et al., 2006).

If SM persists for a prolonged period, it can result in serious mental health repercussions such as depression, social anxiety, and generalized anxiety disorder because the longer SM is left unrecognized or untreated, the more difficult some of the anxiety-related habits are to change (Sutton & Forrester, 2016). The presence of co-existing conditions also means that a person living with the effects of SM through adulthood may need further support to treat these mental health co-morbidities (Sutton & Forrester, 2016).

Those living with SM may feel different to others, especially as they experience adolescent development. Sutton and Forrester (2016) have suggested that people with SM do not always act in ways that others think is socially correct, especially in communication, therefore confusing those who may encounter them. They might also find themselves labelled as unusual or different. People with SM often present a phobia of initiating speech or being overheard in the proximity of a given trigger person or group, especially when these people have previously judged them to be acting differently (Sutton & Forrester, 2016).

Perhaps one of the most serious consequences of growing up with SM is the damage to self-esteem, which affects the manner in which people with SM perceive themselves individually. Sometimes people with SM find that others think their behaviour was intended as a personal insult directed against them (Sutton & Forrester, 2016). Someone living with SM often finds they need to provide more than one explanation about themselves and their behaviour (Sutton & Forrester, 2016).

2.4. Therapy

As discussed above, the aetiology of SM is not clearly defined by the literature. Added to this, SM has co-morbidities that can vary based on individual differences and contextual factors. Given the multi-layered presentation of SM, treatment options are similarly diverse. Treatments have been known to include individual behavioural therapy, family therapy and psychotherapy, alongside the use of antidepressants and anti-anxiety medications (Wong, 2010). Co-morbid psychiatric conditions that are specifically associated with SM include depression, panic disorders, dissociative disorders, obsessive-compulsive behaviour and Asperger's disorder (Wong, 2010). Treatment for children living with SM at school however still appears rare, with fewer options for adolescents.

Clinically, however, greater attention has been given to SM since it has been included under the anxiety category in DSM V. The literature suggests that a nearly universal characteristic of children with SM is anxiety and observes that SM may actually be a symptom of social phobias and other anxiety disorders, rather than a distinct disorder (Cohan et al., 2006). This means that treatment for SM has been confounded with treatments for anxiety disorders. However, when

someone living with SM seeks support specifically for SM symptoms and not for anxiety, it appears as a distinct disorder that requires more attention than any possible co-morbidities.

2.4.1 Behaviour modification

Selective mutism is considered to be a challenge to treat, and the literature on treatment for SM is dominated by case studies and a lack of further developed paradigms (Oerbeck et al., 2014). Most therapies suggest using behavioural or eclectic interventions, though mostly behavioural approaches are chosen (Oerbeck et al., 2014). Treatment delays after diagnosis or identification could be explained because practitioners are not as well informed about SM, or because the information between school and home does not reach the practitioner.

Behaviour modification has been used as a common treatment for SM. Behavioural Therapies include using cognitive behavioural techniques that make use of systematic desensitization, positive reinforcement, modelling, fading, guided imagery and controlled life exposure (Ponzurick, 2012). A team approach for treatment of students with SM is vital as the teacher typically acts as the person who refers the student to support teams and staff members (Ponzurick, 2012). Psychodynamic therapy approaches are also a form of treatment used for children living with SM. These can be based on individual play therapy. On the other hand, cognitive behavioural therapy is typically a multimethod approach that accounts for symptoms in the broader context of the child's environment. This approach may implement specific techniques, including reinforcement, stimulus fading, token procedures, shaping or prompting, contingency management, self-modelling, and response initiation, providing more empirical data-substantiating efficacy (Wong, 2010).

Treatment outcomes of children with SM suggest that although some improvement may occur spontaneously, the majority of clients remain challenged by the condition and therefore remain symptomatic as they go on through their development. An argument, however, can be made for early intervention as it may be particularly important in addressing many of the challenges that come with living as an individual with SM at any age (Cohan et al., 2006).

2.4.2 Emotional regulation

Most SM information appears in psychiatric, psychology, social work and counselling texts; much less appears in paediatric texts. One of the challenges of SM lies in the process of being able to identify what SM is and how it presents. It is thought this identification may need to be supported by other theories on emotional regulation (Scott, 2012). Emotional regulation related behaviours such as asking others, or speaking that develops over time, are context-dependent for each individual. More deliberate or conscious emotional regulation strategies occur as the child's cognitive abilities mature and grow. Some children may be particularly vulnerable to using poor emotional regulation that becomes reinforced and more patterned over time if not intervened or changed (Scott, 2012). For a person affected with SM, it can be seen that they are struggling to regulate their emotions and anxiety in certain situations and contexts, which manifests in them becoming mute.

2.4.2.1 Polyvagal theory

Modern neurobiological framework like the Polyvagal Theory (Porges, 2011) have attempted to explain the manner in which emotional regulation can be addressed with applications to the treatment of SM. As a suggested framework to understand how SM is displayed or occurs, polyvagal theory draws on an evolutionary model of the autonomic nervous system (ANS) in mammals (Porges, 2011). In humans it specifies two distinct functionalities of the vagal nerve, going through different organs of the body and part of the autonomous nervous system. The branches of the vagal nerve serve functions in the evolutionary stress response in mammals; the more primitive branch is responsible for eliciting immobilization responses and the more evolved branch is linked to communication and self-soothing behaviours (Porges, 2011).

As there is limited literature of the exact aetiology of SM or nature of the condition, polyvagal theory and heart rate (HR) monitoring could aid in creating new data and literature of SM for children, adolescents and adults living with SM. There is currently no gold standard for measuring physiological responses to emotional arousal in most individuals. Cardiovascular measures such as HR and heart rate variability offer relatively easy, non-invasive measures of sympathetic

and parasympathetic responses to external stimuli. Heart rate variability, or the measure of the variation of beat-to-beat intervals, has become increasingly used in psycho-physiological research (Porges, 2011). Respiratory sinus arrhythmia (RSA) is an index of cardiac vagal activity related to respiration that offers a direct examination of parasympathetic activity within the ANS. Fluctuations in HR associated with breathing and activity of the vagal nerve are measured in RSA. The vagal nerve transmits information bi-directionally from the brainstem to various organs (Scott, 2012). Thus, the vagal nerve can be considered a feedback system between motor and sensory pathways, and brain structures that monitor, change and regulate sensory input and motor responses (Scott, 2012). Studying the vagal nerve could create a pathway to understanding more about SM, including its aetiology and occurrence rates, especially if teenagers and adults were to be included in further studies.

For a person living with SM, a connection between the visceral state and emotional expression can be made or seen in certain behaviours. It can be seen in the trauma that means the body almost holds a score sheet and that the memory of the trauma is encoded within the visceral experiences, which could manifest in the forms of heart-breaking and gut-wrenching emotions, in autoimmune disorders, and in skeletal muscular disorders (Porges, 2011). The visceral state colours how a person sees their surroundings. The physiological state the person is in precipitates very different outcomes in response to the presentation of the same stimuli or stress (Porges, 2011). Most people are able to gauge danger and feelings of love by gut instincts, which accurately detect how relative the danger of the situation is (Porges, 2011).

Someone who may feel the effect of SM may display immobilization behaviours when trying to speak in certain situations (APA, 2013). In the context of this theory in relation to other anxiety disorders, the place of fear as an emotional response to real or perceived danger can be distinguished from anxiety as the latter is more an anticipatory response to danger. Panic attacks, on the other hand, are a feature of anxiety disorders (but not limited to them) and are a response to a perceived or real threat (APA, 2013) and therefore people with impaired social engagement systems are prone to misinterpret safety as a threat, and objective danger as safety (Porges, 2011). The visceral system then fails to protect them, or prevents the person from engaging in the fullness of life. A

person living with SM may interpret things differently to someone without SM when faced with certain stressful situations. Polyvagal theory challenges the implicit dualism between Western medicine and mind-body problems or challenges, suggesting instead that a parallel set of functions and experiences are informed by both (Porges, 2011). Through the process of evolution, human neural circuits in the brain that were originally involved in immobilization behaviours were modified to serve intimate social needs. These brain structures grew receptors for a neuropeptide known as oxytocin (Porges, 2011).

Gearny et al. (2008) suggest that polyvagal theory provides a comprehensive framework for conceptualizing the physiological basis of effective emotional regulation, which is critical in adaptive behaviour and understanding the immobilization of the vocal chords in children with SM. Polyvagal theory holds that this is done through the dynamic control of cardiac activity, which aids social interaction, focused attention, defensive responses and self-soothing. This can be linked to areas such as socializing with others, contextualizing of a situation, and adaptive responses (Gearny et al., 2008).

Sutton and Forrester (2016) have suggested that often a person living with SM will find that their SM has a lot to do with other people, and also certain aspects of their own life that they need to have some management over. For instance, the minute they are expected to sit with someone who keeps saying or asking for instant changes in their SM, which they know takes years, SM can become present in that situation. It is suggested that when a person living with SM is placed in a stressful situation, the limbic system breaks down and, especially under extreme stress conditions, the social vagal system can no longer stabilize the person. The psychological cohesion of interpersonal neurobiological communication between people breaks down, and the psychogenic system will regulate the metabolic output to cope with the situation (Porges, 2011).

2.5. Children and Adults with Selective Mutism

2.5.1 Experiences of children with Selective Mutism

Early life experiences define the manner in which a person creates narratives of their lives (Wilkinson, 2010). For instance, early life experiences can influence the manner in which somatic and nervous system changes take place, regardless

of whether the experiences are externally or internally experienced. Emotions involve the whole body in adapting to the environment or to any new challenges occurring at any given moment (Wilkinson, 2010). Sutton and Forrester (2016) have also observed that societal speech rules place multiple demands on a person with SM, resulting in emotional stress. For this reason, those with SM can live double lives and modify their personalities to adapt to social situations.

Part of the debate about the development of SM in childhood relates to whether or not SM is a variant of anxiety disorder, which is a result of a combination of a sensitive biological temperament and environmental influences. It is argued that SM has a too complex aetiology to be deemed an anxiety disorder and should retain its classification in the DSM IV under other disorders of infancy, childhood and adolescence (Anstendig, 1999), though later corrected in the DSM V. The effects of living with SM are especially clear when it comes to establishing relationships with others and specifically in the educational context, where socialization is an imperative.

Researchers believe that SM is actually a symptom of anxiety, which reflects a different vulnerability. It has even been suggested that communication deficits and neurodevelopmental delays may also be a part of the underlying cause for the anxiety expressed by SM sufferers (Cohan et al., 2006). It is suspected that younger children with SM would benefit from what older selectively mute people could tell them about their experiences, finding succinct support being the primary objective in order to learn to speak freely and manage the anxiety aspect of SM (Oerbeck, Stein, Wentzel-Larsen, Langsrud, & Kristensen, 2014).

As SM can have symptoms of anxiety it has contributed to the lack of awareness or dissemination of knowledge of SM as a condition. As paediatricians can potentially miss diagnosis, it becomes vital for schools to have plans and programmes in place to get SM diagnosed quicker so as to facilitate access to needed resources (Ponzurick, 2012). This is because children with SM usually speak at home but are mute in other situations, such as school or other social environments (Trainor, 2016).

The anxiety that occurs in conjunction with SM can mean that the person with SM is often described as having a 'deer in the headlights' response when expected

to speak. There are many myths about SM children, including that they have been traumatized or are being stubborn (Trainor, 2016). With their anxiety around speaking, children with SM often do not want any attention from others – even birthday parties can seem overwhelming – and eye contact can be difficult when others are speaking to them. Early intervention with selectively mute children is crucial, and the longer SM remains untreated the more difficult it is to treat. (Trainor, 2016).

2.5.2 Experiences of adolescents and adults with Selective mutism

As children grow up, they may experience debilitating challenges such as peer isolation, few friendships, incomplete verbal academic tasks or participation, or lack of social skills (Vecchio & Kearney, 2009). These challenges can follow a person with SM into their teenage development and adult life. Someone living with SM can find that from an early age that they need to be resilient in social situations that they may not have expected, especially when trying to connect to their peers.

Adolescents with SM have already lived partially silent lives, and though they get by, schools often make accommodations for them, which enables the silence. A person living with SM frequently has fewer friends, since being a silent friend is not easy and speaking has the potential to draw attention to themselves and encourage certain expectations from them (Trainor, 2016).

Suggestions about the adult rates of incidence are underestimated as there is a lack of collected evidence, however the incidence rates are thought to be 2 in 2400 (Sutton & Forrester, 2016). Though diagnosis and intervention rates are improving, adults with SM are significantly less likely to have received diagnosis or help as children (Sutton & Forrester, 2016) than those with other anxiety disorders.

Some adults with SM will say they have improved a lot since their childhood but find that SM has persisted across their developmental trajectory (Sutton & Forrester, 2016). Often being silent seems as natural as breathing. Someone living with SM can talk to those they trust, who support them, who take the time and effort not to judge but to understand (Sutton & Forrester, 2016). Often, however, someone living with SM has to find their own answers. For teachers it is important

to be aware of this context in order to gain some understanding of what their student may be facing.

As Sutton and Forrester (2016) suggest, adolescents or adults with SM often struggle to cope with their day-to-day life. Approximately 20% of people with social anxiety disorder suffer some kind of dependence such as alcohol abuse or drug abuse (Sutton & Forrester, 2016). However, when seeking help an adult living with SM can confront further challenges. Therapists from mental health services often claim to have no experience working with SM and therefore feel limited in their ability to provide help (Sutton & Forrester, 2016).

2.6. Education

The education system can be seen as a dynamic entity maintained by the mutual interaction of its component parts. A system can contain larger parts and smaller parts that are deeply interconnected (Nichols & Davis, 2017). Approaching education from a systems perspective, it can be seen that people's lives are shaped by their interactions with those around them while at school (Nichols & Davis, 2017). For those with SM this means that having experiences at school or elsewhere that are negative or involve a lack of understanding from others can create the idea that they will never be accepted.

Selective mutism can be identified in early childhood while children are adapting to (pre-) school. Those living with the effects of SM often desperately want to have a normal life where they are not treated differently, especially while at school (Sutton & Forrester, 2016). People living with SM can also hold the belief that nobody could possibly love someone who could not speak to their parents and other relatives (Sutton & Forrester, 2016). As an anxiety disorder, SM can be worsened by experiencing anxiety provoked by life experiences or disruptions, including going to school or other social activities. Living with SM often means it becomes an instinct or compulsion (Sutton & Forrester, 2016). The nature of the education system can play a large part in how a student with SM adjusts to that phase of their lives.

According to Giroux (2015), current trends in educational paradigms are seeing young people become almost robotic in their socialization into society, with theoretical approaches that embrace and value a rationality in which ideals of

justice, values, ethics and power are erased from any notion of teaching and learning. As a result, a student who has been living with SM may find that the existing system holds no place for them. Current paradigms have changed the manner in which students are approached by teachers, due to the pressure to achieve certain designated outcomes. Such a context makes it even harder for them to relate to what could be happening to a student with SM who is outside of the expected social norms.

The knowledge a teacher holds about SM could be vital in understanding any students they encounter who are living with SM. Splitter (2009) states that when a teacher or tutor can approach a student from a place of knowledge and understanding, it adds a level of authenticity to their rapport built with students, and could mean the difference of engagement versus non-engagement. The concept of authenticity is familiar in philosophy but is relatively new in the field of postmodern education (Splitter, 2009).

Authenticity, alongside a critical engagement approach, enables professionals to act with a common set of ideas about social norms that offers insights in the educational context when working alongside a student who is living with SM (Giroux, 2015). According to the theory of constructivism as applied to education, the individual is at the centre of the social process, with the focus on learning rather than on how to generally teach (Kala, Isaramalai, & Pohthong, 2010). This theory suggests that there are multiple ways to understand knowledge, that reality is created by an individual's personal contexts, and that knowledge comes from a personal interpretation of the interactions with the world around them (Kala et al., 2010). This theory may inform an exploration of SM sufferers' educational experiences and how these elements are interconnected.

In addition, constructivism can support a transformation from teacher-centred to learner-centred education when approaching students with SM in an educational setting. Constructivism, which is influenced by the work of Piaget and Vygotsky, encourages students to build their own body of knowledge based on their own individual experiences and apply this knowledge directly to their environment (Kala et al., 2010). This approach allows a person with SM to develop self-knowledge function and learn how to address the challenges they face. The ability to critically reflect as individuals, professionals and students draws

attention to ways in which personal knowledge, power, desire and experiences can be made rich and rewarding. These are produced in certain conditions of learning, and raise awareness of the role that learning pedagogy and paradigms play in struggles over assigned social meanings, or modes of expression within a context for a student living with SM (Giroux, 2015).

Integrating a critical engagement approach with constructivist learning theory would support teachers to situate learning within a larger constructivist way of knowing that acknowledges multiple socially constructed truths, perspectives and realities versus a single reality. Constructivism assumes that meaning and values can differ for different individuals, and has the potential to inform the constant negotiations between teachers, students and students who are living with SM. It is interpretive and involves a constant comparison of differing interpretations (Hunter & Krantz, 2010). Developing an awareness of differing interpretations among the students and teachers in education, and in mental health services is an essential part of professional cultural competence in a country with an increasingly diversified population (Hunter & Krantz, 2010).

2.6.1. Critical Thinking

Education has the potential to create the conditions for producing students and citizens who are critical, self-reflective, knowledgeable, willing to make moral judgements and act in a socially responsible way (Giroux, 2015). This potential is especially important for someone who is living with SM, as then they are given the tools and knowledge to be able to make sense of something for themselves, before others are involved. It is crucial for educators to not only connect their classroom knowledge to the experiences, histories and resources of their students within the classroom, but also to create links to further their capacities to be critically responsive to the importance of collective struggles, as well as their individual struggles (Giroux, 2015). Such links could be drawn between students who are living with SM and their peers, in a manner that is supportive and compassionate. These connections can facilitate the understanding and support, allowing a student living with SM to relate with their peers and communities.

Hunter and Krantz (2010) suggest that learners who can explore old and new ideas through collaborative peer discourse and reflection can support other

students to construct new meanings through conversations and interactions with each other and the teacher. This is done within a process of integrating differences with one another, negotiating meaning of the social contexts, and continually restructuring thinking which is a basic concept within constructivism (Hunter & Krantz, 2010). This allows an opportunity for someone who is not fitting into the socialized norm to be able to participate in society without experiencing judgement.

Giroux (2015) notes that by thinking critically students can engage in their own learning from a position of sole personal independence and actively participate in the narratives of their own identities through a culture of open questioning. This would enable a student who is experiencing life with SM to be able to introspectively know themselves and even be able to identify the support they require for themselves. This in turn opens up a space of translation between private contexts and public contexts, while changing the forms of self and social recognition. This could give someone living with SM much greater capacity to positively impact their education and their life in general.

2.6.2 Applying critical engagement and critical thinking to learning environments

A critical engagement approach also maintains that the use of technology in educational settings is crucial. Classrooms should have a well-balanced use of media and technologically mediated knowledge that constitutes a terrain of popular culture (Giroux, 2015). For a person with SM this could mean having greater access to the information already available from an educational setting.

When applying a critical approach to change the life of a student living with SM, the process must be interdisciplinary and radically contextual in order to engage the complex relationships between power and knowledge, critically address the institutional constraints under which teaching takes place, and give focus to how students can engage in critical social citizenship (Giroux, 2015). At the same time, it is important to pay attention to the negative and demanding views of other students, as well as increase awareness that those views may have serious consequences on students' living with SM and who may be subjected to and depend on the intervention from other agencies (Giroux, 2015).

Critical engagement can help to illuminate classroom encounters and synthesize and demonstrate the meanings that a student living with SM draws from such interactions, allowing them to find a way in the system (Giroux, 2015). This also functions as a part of a larger project to contest various forms of domination and to help students think more critically about how existing social and political arrangements might be better suited to address the promise of positive changes in their lives (Giroux, 2015).

The critical approach and reflection can be applied to almost any context. The outcomes of critical assessment can always be related to the specific elements such as SM students, teachers, parents, communities and also resources that are made available (Giroux, 2015). This includes the information that is held, what is known about a subject or condition like SM, and how this can be approached.

Giroux (2015) considers educators as public intellectuals who become responsible for linking the diverse experiences that produce knowledge, identities, and social values in the classroom to the quality of morals and ethical reflections in wider society. To be this kind of teacher means not only educating students to perform jobs, but also teaching them to question critically the institutions, policies and values that shape their lives, relationship to others, and their connection to the larger world. This means encouraging of a form of worldliness within students' needs to include bringing complex ideas into the public space and making use of theory to change things that may seem unchangeable (Giroux, 2015).

2.6.3. Transformational learning

Transformational learning, meanwhile, is defined as the process by which students and tutors transform challenging and problematic frameworks, mind-sets, meanings, perspectives, assumptions and expectations to make them more inclusive, discriminatory, open and reflective, enabling changes in thinking and experience (Illiers, 2009). Some of the ideas and mind-sets addressed in transformational learning can include sociolinguistic ideas, moral and ethical dilemmas, addressing learning styles, and addressing religious views and practices. This includes creating the space to address the existing psychological theories and practices leading to ideas about health and aesthetic belief and value

systems (Illiers, 2009). Such a type of learning would mean that students are learning as much as their teachers or tutors about who they are, the world around them, and how they might approach their lives.

Transformational learning is a demanding process in a learning situation and can affect change at the very core of a personality or identity. It occurs when a student is faced with a disorientating dilemma that redefines how they view themselves or the world (Illiers, 2009). This will often only occur in some specific or special situations of profound significance to the student. Where a new learning or situation is expected to occur in a transformative setting such as education, some people will react by mobilizing a genuine identity defence which can only be removed by a strong therapeutic personality. Such transformative situations occur more frequently in the modern globalized education society of today than in previous generations (Illiers, 2009).

Transformational learning also needs to be clearly distinguished from an informational kind of learning, and each element needs to be recognized as valuable in any learning environment, activity, discipline or field. Transformational learning would allow learning that a student with SM has gained from other assessment methods to be equally weighted with assessments which require speaking or other academic tasks that require verbal participation (Illiers, 2009). Students are then represented by the continuous and consistent interactions between themselves and their environments. Learning then holds the same meaning as experience, and can include emotions, aesthetics and ethics as well as knowledge. With this approach a person with SM could undergo schooling and learning that could be transformative in nature (Illiers, 2009).

In relation to this approach of leaning, elements of John Dewey's theory are also illuminating. For Dewey, knowledge is a state of an individual consisting of a set of beliefs, which may be thought of as habits of behaviour that have been successful in life thus far (see Stokes, 2007). However, when this habit is disrupted or challenged, the individual will need to intellectualize the experience to gain clarity or to resolve the challenge that has presented itself (Stokes, 2007). Working alongside students with SM, a teacher's primary aim would be to reduce the feeling of anxiety and to convey a sense of understanding to the student (Ponzurick, 2012). The teacher may also need to consider referring the student to

a relevant professional or service which can further support them in or outside class.

2.7. Summary

The literature review presented in this chapter began by describing both historical and current understandings of SM before surveying educational theories and showing how a critical engagement approach together with a constructivist perspective could support the educational experiences of someone living with SM. In addition, literature related to therapeutic services and treatments that have been used with people with SM was discussed. Finally, this chapter also outlined some recent neurobiological approaches such as polyvagal theory and how this could be used to describe the aetiological nature of SM. Selective mutism has a chronic trajectory and additional longitudinal research and data are needed to add to the current knowledge of this trajectory.

The literature was found to be conflicting in terms of how and why SM appears, with existing studies being mostly aimed at children. Research on SM has increased in recent years in an effort to better conceptualize and treat it. One area of focus still not receiving enough attention, however, is how educational experiences impact those with SM (Vecchio & Kearney, 2009). Such a focus could also usefully be extended to adolescents and adults to help determine how education can play a part in the identification and support of SM. This research has therefore been designed to fill this gap in the knowledge by exploring the experiences of adults who suffered SM during their school years. This includes whether information about SM was sent home to parents in a manner that was useful or helpful. The next chapter describes the methodology adopted for this study.

Chapter 3: Method

The aim of this study was to research the educational experience of adults who have lived with SM, and how they experienced living with SM during their school years. As addressed in the previous chapter, the literature and clinical research to date suggest that SM is not as common in adolescents or adults as in children, in whom it is not always easily recognized during the school years. This means that support or treatment often is not given until someone living with SM actively seeks out support as an adult.

In this chapter the methods adopted for this research are discussed and explained. The chapter begins by introducing the research. The research used was qualitative, using a questionnaire as a tool for data collection. The questionnaire was used to gather the storied lived experiences of participants. A description of how participants were chosen follows, including the ethical considerations taken into account. This leads to a brief overview of the thematic analysis, the method used to analyse the collected data, and lastly a discussion about the cultural considerations of this thesis which concludes the chapter.

3.1. Aims of the study

The research question of this study was:

How do adults living with SM recall their experiences at school?

The aims of the study were:

- To collect the experiences of adults who have lived with SM from childhood to adulthood.
- For the participants to be able to tell their stories about their experiences with school, peers, family, support services, and how SM has affected them as they grew older.
- For the participants to be able to suggest ideas or recommendations of what they thought may be needed to change the current approaches to managing SM.

3.2. Research design

The approach chosen for this research was qualitative with the collection of stories and experiences of participants from their own perspectives. Lived experiences can be stories told by an individual and they can begin between parent and infant from early development, during which time clues about language, name and social norms can be detected, thus affecting our emotional nature to bridge the simple raw narratives that become personal truths (Wilkinson, 2010).

A qualitative enquiry suited this research as it fit the purpose of allowing the participants to extend and unfold their personal experiences from their own perspectives, in the form of written recollections in a retrospective manner. This method facilitated participant's descriptions of living with SM and how this had affected life during their school years. As Polkinghorne (2007) argues research like this helps to convince the readers of the likelihood of the phenomenon and strong evidence can serve as a basis for understanding of actions or ideas far beyond what may have previously been discovered or thought of in regards to SM.

3.2.1 Analysis and presentation of data

The process of analysis and presentation of data within this method, suggests that the researcher stay closer to the participants' data, familiarising herself with it and identifying patterns and common themes. Whereas other qualitative approaches can at times aim to develop concepts and analyse data, the final product of this research qualitative approach was to explore participants' experiences in a manner in which they use their own language and expressions (Neergaard, Olesen, Andersen & Sondergaard, 2009).

The chosen topic of this research also suited the qualitative approach, as it alludes participants to tell their personal stories from their own perspectives with no other influences. This approach was applied through the questionnaire in an open-ended manner to explore with the participants their ideas about what had happened to them, how they felt their education had been affected by SM, and what they thought could have been done to support them effectively. The open-ended questionnaires allowed the researcher to collect the

experiential stories from participants. As a methodology this provided the opportunity for volunteer participants to describe their own personal stories.

Approaching the research from a qualitative perspective, it was important to look for ways to understand and then present the very real-life experiences of the participants, through the careful re - telling of the stories that participants told about their experiences as described by the participants (Wang & Geale, 2015). This allowed for contextually rich descriptions of experiences, with details and intrinsic meanings that participants had derived from their experiences as adults with SM looking back over their time at school and through other areas of their lives. According to Wang and Geale (2015), making use of a qualitative inquiry like this helps to amplify the voices that may have otherwise remained silent.

The experiences of individuals affected by SM tells a unique story of human existence which is filled with continuous experiences of interactions and narrations, with the surrounding world and individually. All of this is woven together into a seamless web, which is complex in its construction. Experienced stories are important to help structure a worldview and the information constantly bombarding us in modern society makes these narratives of experience data rich. Narratives can be transmitters and producers of reality, during which social construction can introduce other ways of interpreting life socially and culturally (Moen, 2006).

3.3 Participants

To recruit participants, this research study made use of the social media platform Facebook. This enabled the participants to be invited and recruited online and to later be contacted on a one-to-one basis. The use of Facebook enabled the research to have an international scope. Recruitment was done by making use of an advertisement (Appendices 1 & 2) which was posted to particular Facebook group pages, all of whom represented communities and awareness groups for people with SM. If participants were interested in participating, they could either send the researcher a private message in Messenger (Appendix 3) or 'like' the advertisement to receive the information. In a private message prospective participants were encouraged to supply an email

address so all conversations could be completely private and out of the public eye.

The groups that the advertisement was posted to were:

- Selective Mutism New Zealand
- Selective Mutism Australia
- Selective Mutism Recovery
- Selective Mutism
- Selective Mutism Awareness
- Selective Mutism in Ontario Canada
- Selective Mutism in UK and Ireland find others who live close to you
- Our SM Recovery
- SM Space Café
- Selective Mutism (SM) Awareness/support
- Selective Mutism: Do not dismiss as shyness

Participants were selected from the volunteers using the following criteria:

- All participants were adults (above the age of 18).
- Participants had been identified as selectively mute either by diagnosis or by self-diagnosis through other channels.
- Participants were not in current psychiatric care or treatment for SM.
- Participants volunteered to participate and tell their stories of past experiences as living with the effects of SM.

Prospective participants were informed about the research by an information sheet (Appendix 4) that was sent to them as a soft-copy document attached to an email. Once they had read and confirmed that they would continue, the consent form and questionnaire (Appendix 6) were sent via email, as an attachment. Participants were then asked to fill out the questionnaires. Some of the questionnaires were not returned due to some people's lack of computer skills (difficulty in opening the documents). Ultimately seven participants were recruited for this research.

3.4 Data collection method

Qualitative enquiry enables the researcher to answer when and where based questions and ensure that the behaviour or answers of the participants cannot be manipulated or influenced. It also allows all contextual information to be presented, as boundaries between phenomenon and context is not clear. As already stated, the data collection method was a questionnaire (Appendix 5) which was distributed via email, as the nature of participants being SM, or self-identified as SM, means it is more likely to collect information which is rich in narrative contexts when participants can provide that information in their own time and in the privacy of their own home (Baxter & Jack, 2008). No word limit was set to the questionnaire answers with the intention of collecting detailed narratives that showed clear themes and ideas.

The questionnaire was developed by the researcher with the support of her supervisors. Questions were open ended in order to facilitate the expansion and details of participants' stories. There was a small pilot study conducted with two other volunteer individuals. This was done prior to the main research study to ensure the reliability of the questions. The feedback received was used to reword some questions. Questionnaires then were distributed online by email or through the use of social media.

3.5. Data Analysis

The approach used in this research focused on the use of stories, as stories are integral to human culture because of how lives and realities can be constituted through the collections of stories told about how people live and see the world. It is these lived realities and cultures that create the conventions for living in an expected way. Whether it is in the general community, workplace or home, the ideals created can shape the way individuals envisage their world and speak about their place within it (Fraser, 2004).

In order to make sense of the emerging qualitative data, analysing the commonalities in the participant's stories was part of the process. The analysis of common ideas in participants' stories is essentially a method for identifying and analysing patterns in qualitative data (Clarke & Braun, 2013). For the purposes of this research, the information from the completed questionnaires were entered

into in an Excel document, with the answers to each question grouped by question number, which made the common ideas in questions easier to identify. Eventually this led to paraphrasing of each set of data into participant profiles (see Chapter 4) as a manner of protecting some of the really painful memories expressed in the raw data, which participants had agreed with during the initial email recruitment process.

Analysing for common ideas was used to establish relationships between the most common emerging themes throughout the participants' stories (see Chapter 5). The participants who had completed the questionnaires data was gathered and arranged in themes after systematic reading and rewriting into profiles that made the correlations more clear. Those themes or correlating ideas were drawn from the main themes for the discussion in Chapter 6.

The themes and emerging patterns within the data were important to the description of an experiences of the participants and were linked to the research question. In this research, the following key themes were identified (see Chapter 5):

- Recognition of Diagnosis
- Educational Experiences
- Emotional Experiences
- Family Experiences
- Help Seeking
- Selective Mutism Spectrum (SMS)

As part of this research, a small amount of demographic information was collected to give an idea of where in the world participants were, their age and gender, and whether they were in employment. Fraser (2004) suggests that it is important to emphasize curiosity and reflexivity throughout research and the analysis of the themes with the analysis being reflected on carefully to choose themes that are put forward. Bryman (2006) adds that researchers should include information about whether qualitative and quantitative data are collected simultaneously, and which of these are the main priority of the research. These considerations were taken into account in the data analysis phases.

3.6. Ethical considerations

3.6.1 Use of social media

Buchanan and Markman (2012) state that the internet is a social phenomenon, a tool, and also a field for research. Depending on the role the internet plays in the research project or how it is conceptualized by the researcher, different epistemological, logistical and ethical considerations will come into play. The term 'internet' serves as an umbrella for innumerable technologies, devices, capacities, uses, and social spaces. Within these technologies, many ethical and methodological issues arise and, as such, internet research calls for new models of ethical evaluation and consideration. The use of social networking by means of Facebook was used for this research. The popularity of online social networking sites such as Facebook, Instagram and Twitter has attracted attention from many researchers and disciplines (Zimmer, 2010). The use of Facebook can be seen as a challenge for valid data collection, and can raise some questions about confidentiality. For this research, however, participants' privacy was ensured as only the initial recruitment phases were done publicly.

After the public post, interested participants either made contact via a private message on Facebook messenger or email; both of these platforms were password-protected and the information was not accessible to anyone other than the researcher. Recognizing the privacy concerns that were attendant to the collection and release of social networking data, the researcher took various steps to protect the identity of the subjects, including the use of private inboxes, and a mobile phone number was provided to make use of texting if needed. Further to this, the raw data taken from the original questionnaire was categorized using identification numbers. This is what was later used to create the paraphrased profiles which made use of the pseudonyms.

All data was stored as soft copies once received by the researcher, with the original hard-copy questionnaires destroyed after their data had been stored electronically. The electronic data was saved to memory stick which was held by the researcher while the research was happening, and is now stored in a locked facility with other files that are only accessible by the researcher. No other person other than the main researcher and her immediate supervisor ever saw the raw

data before it entered the analysis phases. All other identifying information was removed from files. At this stage all trace of research-related information was removed from Facebook's public sphere and the internet. While occasional informal updates were posted on groups that had previously been posted on by the researcher, there was no formal identification of the research process or data presented.

The available data in such an open process could have been skewed due to self-reporting biases and errors by the research, which can fail to reflect the true depth and complexity of the information users submit on social networking sites (Zimmer, 2010). While this must be taken into consideration, participants in this research had experienced SM for most of their lives, and had gone through school as someone who was perceived as different. Considerations had to be given to participants being vulnerable, as they may have experienced stigma, bullying and other potential mental health challenges. These considerations meant that the information sheet (Appendix 4) contained information for support services. The information was mostly, however, related to support services outside of New Zealand. New Zealand services were not included as the researcher would have been able to connect participants from New Zealand to services if requested.

Ensuring the rigor of the research also required that the biases of the researcher were considered. As the researcher is an adult with SM, the effects of hearing stories that may express painful memories may have added challenges. There may also have been a bias towards favouring certain themes over other themes. Though it is aimed that the researcher remain objective the findings were analysed by the immediate supervisor as well to ensure that all elements are considered and included in the findings and then the discussion.

The analysis of data from the research participants needed to be done carefully, considering that the stories are deeply personal to the participants. This was achieved by making the process private after the initial call for participation and by remaining in contact with participants throughout the whole process of filling out the questionnaires and writing their narratives. This included giving all participants the opportunity to withdraw from the process of research if they felt they needed to and giving them pseudonyms.

It is important to note that participants' right to privacy exists both as a moral and legal right. This right is not absolute, however, if they or another is deemed to be at risk. This must be made explicit within the informed consent process. In addition, the methods of recruitment must be clearly outlined within the research protocol to ensure that no coercion occurs (Greaney et al., 2012). Participant confidentiality was protected in this research by collating the data into paraphrased profiles, for which all names and personal details were changed. Participants that chose to be a part of the research were from a wide variety of countries and cultures. This research study was approved by the Whitireia/WeITec Postgraduate Board of Studies and a letter was received stating this (Appendix 7).

3.7. Cross-cultural considerations

This research makes use of nominal Māori terms as a manner of recognising the importance and contribution of Te Reo Māori to a uniquely New Zealand identity and to address the principles of Te Tiriti o Waitangi, which are partnership, protection, and participation (Clements, 2016). This is to normalize the use of Te Reo and to value and validate it as an integral part of New Zealand identity. In this any barrier to participation was avoided (Clements, 2016). This research aimed to address the principles of Te Tiriti by being culturally inclusive to any Māori or any person from New Zealand who wished to participate, while still being a part of wider cultural model of research with other ethnicities. This was achieved by the inclusion of specific terms or words within the questionnaire that were in Te Reo Māori.

Kaupapa Māori approaches permeate cultural beliefs that have contributed to a minor cultural revival (Henry & Hone, 2001). Cultural values can serve as trans-situational goals, which can serve as guiding principles in the life of a person or other social entity. Also, this further influences individuals' beliefs about cultural institutions such as family, school, and work, and can affect how people set goals and interpret relationships, expectations, demands and duties in the workplace (Klassen, Usher, & Bong, 2010).

Cultural values differ within a country, and there is much intra-individual variation. They differ across other countries too. Cultural values are linked more

strongly to one's nation than to religion, employer organization or individual personality (Klassen et al., 2010). Participants in this research were from a variety of countries, though all had a command of English. Considering kaupapa Māori approaches while researching and recruiting participants can be utilized in the development project to improve the operational and achievement rates for Māori and all other cultural identities that took part in the research for this thesis (Bishop, Berryman, Cavanagh & Teddy, 2009).

The following glossary of terms was included in the information sheet and the questionnaires:

Māori	English
<i>Whanau</i>	<i>family</i>
<i>Takenga</i>	<i>origin</i>
<i>Kaiuru</i>	<i>participant</i>
<i>ngā tikanga</i>	<i>ethics</i>
<i>Tau</i>	<i>age</i>
<i>ira tangata</i>	<i>gender</i>
<i>Kura</i>	<i>school</i>
<i>nga korero</i>	<i>stories</i>
<i>Kaiako</i>	<i>teachers</i>
<i>kaitiaki</i>	<i>caretaker</i>
<i>whakaaro</i>	<i>ideas</i>
<i>tautoko</i>	<i>support</i>

This chapter has described the methods used in this research, the nature of the research design, the use of social media for gathering data, and finally how the data was analysed by means of thematic analysis and paraphrased participant profiles. The chapter also discussed the ethical considerations taken into account and the questions of privacy, validity and confidentiality, including how data was managed and stored. Finally, the relationship of this research to the principles of Te Tiriti O Waitangi was addressed, which led to the nominal use of Te Reo terms in the questionnaire.

Chapter 4: Participant Profiles

In this chapter the participants are introduced by showing some demographic data and also a short introduction of where they are from. The profiles are anonymous and pseudonyms have been used to protect the identity of the participants.

The data collected in this research aimed to explore the lived experiences through stories told by the participants about experiencing and living with SM while in education. The actual findings from the stories will be paraphrased later in the following chapter. The first part that is introduced here is the demographic data that was collected to gain understanding of where participants were in their stage of life, their locations and gender.

4.1 Demographic Information

Age Range	16 -25	25 -35	35 -45	45 -55	55 -65	
Susan		✓				
Taonga		✓				
Olivia		✓				
Brandy	✓					
Emma		✓				
Decland		✓				
Edna		✓				
Gender	Male	Female	Gender Diverse			
Susan		✓				
Taonga		✓				
Olivia		✓				
Brandy		✓				
Emma		✓				
Decland	✓					
Edna		✓				
Occupation	Student	Stay at home parent	P/T Employment	F/T Employment	Currently not working	Other
Susan				✓		
Taonga		✓				
Olivia	✓		✓			

Brandy		✓				
Emma					✓	
Decland	✓		✓			
Edna				✓		
Country of birth	Australia	New Zealand	United Kingdom	USA	Canada	Indonesia
Susan			✓			
Taonga		✓				
Olivia				✓		
Brandy						
Emma			✓			
Decland						✓
Edna			✓			
Location	Australia	New Zealand	United Kingdom	USA	Canada	
Susan			✓			
Taonga		✓				
Olivia				✓		
Brandy						
Emma			✓			
Decland	✓					
Edna			✓			

Seven participants completed the questionnaire. The seven paraphrased profiles presented here reflect the raw data produced through the questionnaire and showed the participants stories of resilience. The first profile presented is Susan, followed by Taonga, Olivia, Brandy, Emma, Decland and lastly Edna.

4.2. Susan

Susan is a female who identified that she is between the ages of 25 -35 who is currently in full time employment. She is currently living in the United Kingdom. Susan states in her narrative that she knew she was different her whole life, but it was not until she found information on SM at fifteen years of age looking for answers that she knew that this was what she had. After finding a google article, and a program on television, Susan found something she identified with.

4.3. Taonga

Taonga is a female who identified to be between the ages of 25 -35 who is currently a stay at home parent. She was born and lives in New Zealand. Taonga

states in her story that she had been thought to have some form of extreme shyness by her teachers and peers, as she could talk to her closest friends and family, but would only speak to anyone else if they asked a question. It was not until she took her own daughter to the doctor that she was diagnosed with SM.

4.4. Olivia

Olivia is a female who identified herself to be between the ages of 18 - 25 who is currently a student. She is from Canada and still lives there. Olivia wrote that she did not find out that she had SM until she was twenty-one, and had gone many years without speaking in school and most social situations without understanding the reasons behind her behaviour. She did her own research and found a page on the internet and said it suddenly made sense. Though Olivia never received a formal diagnosis of SM, she was diagnosed with Auditory Processing Disorder (APD) which she later learnt is common in others with SM.

4.5. Brandy

Brandy is a female who identified herself to be between the ages of 25 - 35 who is currently a student and also in part time employment. She is from the United States, and is still living there. A counsellor made the suggestion of SM to Brandy while she was at middle school, she undertook her own research to learn more, and was given further information by a counsellor at university.

4.6. Emma

Emma is a female who identified herself to be between the ages of 18 – 25. She is unemployed which she attributes to the effects of SM and Asperger's Syndrome. She was born in the United Kingdom, and is still living there. Emma's parents noticed that she was very shy and would only speak to certain individuals. She was fourteen when she was diagnosed with SM.

4.7. Decland

Decland is a male who identified himself as between the ages of 25 – 35. He is currently a part time student, and in employment. He was originally from Indonesia, but is currently living in Australia. Decland describes reading a book

which he had accidentally picked up in his school library that had a description of Selective Mutism (SM) in it.

4.8. Edna

Edna is a female who identified herself to be between the ages of 25 -35 who is employed full time. She was born in the United Kingdom, and is currently still living there. Edna described her symptoms to begin at the age of three and to be diagnosed by the age of ten, as she had severe anxiety symptoms which continued throughout her schooling. She described seeing a variety of different professionals that weren't helpful, and she hoped that she would grow out of SM.

Chapter 5: Findings

In this chapter the research findings are presented as themes that emerged throughout the data. The findings are illustrated by direct quotes from the raw data as verbatim of the stories described by the participants. The themes transpired from the data are described in this chapter in the following order: Recognition of diagnosis; educational experiences, which includes peer experiences and relationships; educational and academic experience; classroom experiences which then leads onto the heading of emotional experiences which includes sense of isolation; bullying and stigmatization; mental health challenges and long lasting memories. Further findings include family experiences and lack of recognition, this leads onto help seeking, theme that includes ideas such as school and university experiences; support services and other sources of support that participants had told stories of.

The findings then lead onto describing the participants 'coping mechanisms unveiled though the data which include the use of sport and extra circular activities as sources of resilience. These aspects are lastly followed by participant recommendations.

5.1. Recognition of Diagnosis

Participants described SM as a condition that is not commonly addressed. Often, participants expressed how they relied on the media to self-diagnose. The following statements describes the participants' experiences:

I had realized I was different all my life so when I was 15 I decided to google symptoms on the internet and a Wikipedia article came up for selective mutism. I read about it and realized it was like me... Susan

Participants commented on discovering SM via the internet, sometimes after seeking out answers as to why they are as different as they are. As Olivia explains:

I was 21 when I discovered I had Selective Mutism. I went years without speaking in school and in most social situations without ever understanding why. I started researching and came across a page on Wikipedia about Selective Mutism. I was intrigued because I could relate to almost everything written on the

*page. I started doing some further research and received the answers I had been seeking for many years. Suddenly it all made sense. **Olivia***

In some cases, participants discovered while reading something else. As Decland and Susan explains:

*I was reading in the school's library during my senior year of high school (I was 18) and I accidentally grabbed a book (don't remember what book it was) and found a description and a name (Selective Mutism) that matches my condition. That was a light-bulb moment. **Decland***

*I had realized I was different all my life so when I was 15 I decided to google symptoms on the internet and a Wikipedia article came up for selective mutism. I read about it and realized it was like me, and around the same time there was a TV program on about it called 'My Child Won't Speak'. This confirmed I had selective mutism. **Susan***

Formal diagnosis was obtained indirectly by some participants. They were diagnosed while seeking help for something else. For instance, Taonga said:

*It wasn't until I took my 8-year-old daughter to the doctor who didn't speak to anyone except me, got diagnosed with SM. Reading up on it I found a lot of similarities of what I went through and would feel. **Taonga***

In some instances, participants described the practitioner knowing about the potential of SM, but did not diagnose nor referred to any available information about SM, as Brandy explains:

*It was suggested by a counsellor in Middle School when I was not speaking to my teachers. After that, I did my own research and learned more about it. A counsellor recently in college gave me more information on it and basically confirmed the diagnosis. **Brandy***

The diagnosis of SM was expressed by participants by finding out about a different diagnosis first which lead to an unofficial diagnosis of SM later on as is explained by Olivia as follows:

*I have never received an official diagnosis for Selective Mutism, but at a very young age I was diagnosed with APD (Auditory Processing Disorder). **Olivia***

Participants told stories of being able to identify others with similar afflictions, or what they thought could have been SM, sometimes being able to see that others do not cope as well as they do with life. As Decland explained occurred to him while overseas:

*Looking back, there was actually another student that had SM, but none of the teachers knew what to do with her. One teacher tried to approach her with dancing since she wouldn't communicate verbally. I didn't know how it went. I think her SM was more severe than mine. I was a functional SM that suffered through life because I couldn't socialize/make friends. But I was able to do presentations and all the things I needed to do to pass the class, or buying food at the school's cafeteria. **Decland***

Direct diagnosis of SM was reported by participants to be rare, finding it out only when being seen by a doctor for a different reason. As Emma and Edna explain:

*When I first started school at the age of five my parents started to notice that I was very shy and that I wouldn't talk to anyone apart from my close family and a few friends, when I was 14 my chest specialist (paediatrician) diagnosed me with selective mutism as I couldn't say 1 word to him. **Emma***

*The symptoms began at age 3, and I received a diagnosis at age 10. My parents (mother and her partner) had to travel to London to meet a famous child psychologist, Professor Michael Rutter, to get this diagnosed. I had severe anxiety symptoms at the start of school, and continued throughout. **Edna***

Participants described their frustration with the mental health system, as they perceived that professionals did not always have sufficient information about SM to be able to diagnose or treat their condition. Decland explains his experiences as follows:

I tried to be as articulate as I could be, but some of these so-called mental health professionals are still baffled by what I described. One psychologist tried to

*treat me with a technique usually used for a person with PTSD, despite my explanation on how I really didn't have PTSD. (Hell, no! I don't have PTSD!). Another psychologist suspected that I had a mild Asperger's syndrome. Only after an elaborate and exhausting explanation was I able to convince her that I don't have the slightest signs of Asperger's. It's very frustrating. **Decland***

5.2. Educational Experiences

5.2.1. Peer Experiences & Relationships

Participants in this study wrote about their experiences of relationships with peers and teachers. Some described being able to have friends, while others talked about being isolated. Participants wrote that the support from other students did make things easier. For instance, two participants wrote:

*I think it was easy to get by every day because as I said I had friends who were nice and didn't get bullied. I didn't need to adapt myself in any way. **Susan***

*I never really had trouble making friends..... **Brandy***

These statements portrayed a positive peer social experience for participants, especially if they had negative experiences with teachers or relievers. Participants wrote about how in some cases, students would stand up for them against others who may not have understood, as is written by some of the participants:

*Support from other students made the day easier – If we had a supply teacher when our usual teacher was away, other classmates – even those I weren't friends with – would answer the register for me and say 'she is here but she doesn't talk'. **Susan***

*Some of my classmates in grad school have been very supportive. **Brandy***

Another participant also referred to times when she felt treated her "like everyone else" by others, as expressed by Oliva:

Another girl also treated me the same way as everyone else. I was also able to speak to her a little bit, because she didn't patronize me. She was kind to me and looked out for me in some social situations. One time she even went out of

*her way to invite me to sit at her table during a team supper. I remember memories of the people who treated me normally, because most people did not. All I wanted was for everyone to treat me as they would anyone else. I was incredibly socially aware and often heard comments about the “weird girl who doesn’t talk.” I wanted people to realize I was just like them, only the words were trapped inside my head. **Oliva***

Although not all participants had peers that were as supportive. Participants also wrote about how they found social peer interactions challenging, and would have very little or no peer relationships within their own age groups. Some participants stated that they spent a number of years only going to school and then going home, as they had no social peer relationships. As the following participants explained:

*Although everybody was relatively nice to me, I never had any friends to hang out with. My social life includes going to school and going home. There was absolutely no time spent with friends outside school. This continued all the way to the end of high school and a few years during university. **Decland***

*I was okay to answer the register and speak when spoken to, so most stopped challenging the SM. In High school, learning is more structured than it is in previous schools. Some classmates just assumed I was a swat (teacher’s pet who likes school work) or I was stuck up. Others just thought I was shy, and I got the nickname “Edna Shy”. **Edna***

Participants generally spoke about the challenges of social and peer relationships and described similar challenges with teachers. Some participants expressed having some positive experiences, while others reported having difficulties to make friends while at school.

5.2.2. Educational and Academic Experience

Overall participants explained and told stories related to the lack of knowledge and understanding about Selective Mutism while at school. Their perceptions of lack of sufficient support are described by participants in the following manner:

*Because no one at my school knew anything about Selective Mutism, I had little to no support. My soccer coach, who was a teacher at the school, treated me normally, which few people did. She believed in me and I was able to open up to her a little bit. **Olivia***

*The staff at my school were not knowledgeable about Selective Mutism, and neither was I. I think my life could have been a lot different growing up if I had received the support I needed. **Olivia***

Participants described the pressure felt from their teachers expecting them to do certain things or act in a manner that may be 'easier' for students who does not live with SM. As Brandy and Edna explains:

*I remember my 7th grade English teacher trying to bribe me to talk and putting her head down and not looking at me to try to make it easier to talk. I remember this because she was really the first teacher to address my SM (even though we didn't know what it was at the time) and she didn't know how to support me but she tried. **Brandy***

*They implied I was a moron, and that I did not know what money or books were. My mother advised them that I read plenty at home. The teacher's response seemed to be a sarcastic "Whatever, I believe you... **Edna***

For participants, the expectations to be a specific type of students meant that often they were having to find ways within their classrooms to cope with tasks and achieving the tasks, despite of the challenges presented by SM. Whether it was seeking further clarifications from teachers, asking for help, asking to use the restroom, or answering the roll. The expectations from teachers and staff, created further extra pressure to perform as Taonga explains:

*If I didn't know how to do something or understand something when doing my work, I would sit there staring at it, getting worked up inside that sometimes ended up in me producing some tears that I would quickly hide because that would bring more attention than actually asking the teacher for help. I never asked the teacher for help. **Taonga***

Participants explained that they were often marked down based on how they participated with others, as educational curriculum expected this as a 'norm'. Participants were often having to find ways to get by. All participants described themselves as good students and capable of achieving good results, though they thought they could have had higher achievements if they did not present with this condition. As told by Olivia:

*A lot of teachers give marks based on participation. Because I was unable to communicate, my participation grades were weak, which in turn affected my other grades. I was a good student and this bothered me. I remember feeling frustrated when I'd know the right answer, but just couldn't say it out loud. **Olivia***

Having questions asked or presenting in front of an audience were topics that participants especially commented on as adding extra stress and social pressure. They reported always knowing that they could do it, but found that SM was most present at those exact moments, some teaching themselves newer ways to get through their presentations:

*To me it was a horrible and hot 3 minutes, there was no emphasising, no change in tone or gestures, my head was down the whole time, staring at my speech cards and basically mumbling the whole thing. To my class mates, it was probably the most boring and hard to hear speech they've had to listen to, but I did it so I could get my school certificate credits. Before doing them I would have to psych myself up the whole week before so I didn't get up in front of the class and completely freeze, embarrassing myself even more. **Taonga***

Though participants all described the challenges they had while at school, most found that they were academically and intellectually capable of managing their academic achievements. They felt that they were sometimes assumed by the school staff to be less capable, as they were perceived as too quiet, or even defiant, or sometimes defined by other labels. As Brandy and Decland explains:

*In high school I had all kinds of issues with teachers. My Spanish teacher always acted frustrated with me and said I was stubborn. One of my English teachers reported me to the counselling centre but they didn't do anything. I ended up losing points on presentations because no one would help me but I still got A's and B's. **Brandy***

*In class I was treated like a normal person and generally everybody treated me like a normal person – I think the fact that I was one of the smartest kids in class and I was relatively physically big for my age during primary school helps. Of course, they (students and teachers) would sometimes tease me as “the statue”, “the mute”, “the person who doesn’t have any emotion”, “cold-blooded killer”, etc. **Decland***

Though participants described encountering some assumptions about themselves and their capabilities because of their SM, most talked about being able to achieve good marks and being academically capable. In saying this several barriers were described such as being assessed for social participation, presentations or expectations to talk in order to achieve. Decland explains:

*In class I was treated like a normal person and generally everybody treated me like a normal person – I think the fact that I was one of the smartest kids in class and I was relatively physically big for my age during primary school helps. **Decland***

*At primary school I was told I would never make it to high school, and staff like dinner ladies would not let me have lunch etc. until I spoke to them. **Susan***

5.2.3. Classroom interactions

Participants did talk about the comments that were made by their teachers, the staff, and other students. These would often show on their reports, causing questions to be asked by their family members. Participants could also relate how those comments often had negative effects for them, as Decland explains:

*A simple comment “Decland, you’re awfully quiet” would send me to a depressive mood for a few days. I think that is one of the most insensitive comments people could say to me. I think it still would, but it doesn’t happen very often now. **Decland***

Brandy spoke further about her university experience after school, which was also a challenge, and how SM followed her into adult life and tertiary study. She was expected to participate in simulated sessions with clients while being observed, finding that the tutors kept on putting pressure on her, because her SM

was far less pronounced by then, and even though the teachers were asked to stop. As she explains:

*I had trouble in Comp I because the teacher kept pushing me to talk. It was difficult to get references because I didn't participate in classes or talk to the teachers outside of class. I actually got an A in my Speech class. I was able to get into grad school but I had a lot of trouble in my first semester. One teacher was really supportive but she also gave me a 0 on an assignment until I did a simulated counselling session and I know if it was a physical issue, that wouldn't have happened. She also just kept calling on me when I didn't want to speak and even after disability services told her to stop, she still did it. My Diversity teacher just kept calling on me and told me participation was very important in his class but offered no alternative methods for me. **Brandy***

5.3. Emotional Experience

5.3.1. Sense of Isolation

Participants described what it was like experiencing and living with Selective Mutism (SM) and the effects it had on their lives. Many describe how they felt socially isolated from their peers right throughout school, and not having many social groups outside of school. They found that it took time into their adult life to being able to make friends, finding friendships enough of a challenge. Decland explains:

*I went through the first 20 years of life without having any friends. It has been a very rough life, but here I am, alive and breathing. At 28, making friends is still hard now. Mostly because I never learned to do it myself. Just like if you want to learn to ride a bicycle, then the most effective way is to actually ride the bicycle itself, NOT watching lots of people ride their bicycles. I know what normal social interactions look like because I've observed lots of them, but very minimal experience in doing it myself. And don't even talk about girlfriends, because I'm still learning the art of regular friendship. **Decland***

Participants described always having challenging experiences with friendships. These experiences were described more negative than positive. Edna and Decland talked about when recalling their school life:

*I had not made many friends in school and spent every lunchtime in the school library. I became as school library monitor and focused on my work. My grades were always C or above. **Edna***

*Although everybody was relatively nice to me, I never had any friends to hang out with. My social life includes going to school and going home. There was absolutely no time spent with friends outside school. This continued all the way to the end of high school and a few years during university. **Decland***

Like Emma, most participants agreed that at some point they had one friend who was helpful and kind to them, typically during the primary school years. This often changed once secondary school started as Emma further tells her story:

*I only had one friend in my class in primary school who understood me so she would talk for me if I needed help in class. I didn't have many class mates in either primary or secondary school because most people my classes didn't understand me so therefore they didn't bother with me so that made it very difficult for me to make friends at both primary and secondary school. **Emma***

In some cases, for participants, making friends was not too difficult, though they still encountered what they felt to be ignorant comments relating to being perceived as different from their peers. Brandy depicted this in her reflections:

*I never really had trouble making friends. I've had friends say a lot of ignorant things like "oh, why doesn't she have to participate?", "*gasp* she talks!", and "you talk all the time on Facebook and to us, why can't you talk in person? **Brandy***

As someone who had lived with selective mutism, participants could often identify others who had the same or similar experiences, and were able to recognize that SM presented differently for them as it is for others. Susan explained her point of view by saying:

*Other people with SM can't necessarily speak at all, not even quietly, but I can so I think this definitely contributed in people wanting to be my friend – I could actually contribute to conversation even if it was only one sentence a day. **Susan***

5.3.2. Bullying and Stigmatization

Participants describe that since SM affects the ability to speak, it makes it difficult as a person with SM to relate with others. As they described feeling mildly ignored or labelled, these experiences resulted in a form of stigmatisation. They perceived that either teachers or students almost would not bother to try and communicate. Oliva described this in the following quote:

*I went 12 years without any friends and was completely isolated. No one bothered to speak to me because they knew I would not speak back. I would give yes or no answers, but that was about it. I remember one kid said that I was boring because I was so quiet. There was another girl that used to speak really slowly when addressing me, because she felt I couldn't understand her. I felt like screaming, "I'm not stupid, I know what you're saying. The words are just trapped inside me head and can't get out. **Olivia***

As students, participants identified that they have been labelled as being oppositional or defiant, and found that they were sometimes at the centre of attention over negative events that may have been happening. This sometimes resulted in not being able to say anything to argue against what was being said to them which caused them to internalise some of the negative feelings they were experiencing, as Susan explains:

*....so I don't dislike them for it, but I strongly remember feeling guilty, weak, ashamed and helpless, which I think has affected me as an adult... **Susan***

Participants described being labelled and stigmatised by other students as Edna vividly remember in her story:

*At the beginning of infant's school, I was despised by staff. They seemed to have an expectation that I should be playing 'cutesy' for them instead of being silent. I learnt recently that they approached my mother and asked if my father was abusing me? She was appalled and told them no this is not the case. **Edna***

Participants wrote about being treated differently, being judged and having other students making negative comments. Sometimes experiencing hidden or overtly bullying from both students and staff, Susan and Decland described:

*One thing that I remember is someone saying I should kill myself because I am weird I also really remember people answering the register for me, and the teacher who told me I wouldn't make it to high school unless I spoke. **Susan***

*One day, another kid physically attacked me, but I didn't scream, didn't yell, didn't cry, and didn't say anything to anyone until my mother noticed that my face had been hit by something. Only then she contacted the teacher. Then they asked me why I didn't say anything. **Decland***

Decland further described being bullied in ways though it was not physical, still remains a prevalent memories for him:

*I do remember a few of my classmates' conversation in front of me trying to analyse if I had autism. They concluded that I didn't have autism (duh..). But the fact that they had the conversation about me right in my face bothers me a lot. **Decland***

All Participants identified times when the staff or teachers seemed to bully them into pushing them to be more 'like everyone else'. Participants' found that some negative comments from teachers perpetuated a specific social expectation:

*One of my teachers bullied me because I didn't speak in class. One time I couldn't speak out loud and he screamed that, "I was stupid for being shy. People out grow their shyness when they're young and I needed to do the same." To be screamed at for not being able to communicate was humiliating. **Olivia***

*There was one occasion, a girl I did not know just walked towards me saying "that weird girl won't talk" and I just walked away upset but my best friend found me. **Edna***

Participants generally told stories about the assumptions that were made of their capabilities as not being able to speak more socially or during class activities. They described being seen as defiant or rude as they got into their secondary school years, some found themselves being shouted or yelled at when they could not speak as expected. This experience was explained by Susan:

*At primary school I was told I would never make it to high school, and staff like dinner ladies would not let me have lunch etc until I spoke to them. This was obviously upsetting. As I got older, it was seen as me being rude, so when I first started high school a few teachers were rude about me and shouted at me for not speaking. **Susan***

Taonga reported becoming almost a bystander in her own educational journey. Although she could push herself, the extra support could have helped. Taonga narrated her experience in the following statement:

*I think because they did just leave me to get on, I knew it was up to me to excel therefore pushing myself to do what was needed sometimes. I do often wonder if they had pushed me to do things, like have a talking part in one of the productions if it would of helped open me up..... **Taonga***

5.3.3. Mental Health Challenges

Participants said that they would be able to identify other mental health challenges that were also present for them, and talked about their coping mechanisms. For participants, this included the experience of being ignored by the health system, once SM had been identified, and that they were expected to not be able to do as well as it was expected of them by staff or peers. Participants described the strategies they used to face these challenges as Brandy narrates:

*I often had to live day by day and it was a struggle. I would doodle in class to reduce my anxiety but I also got in trouble for that. I started cutting myself in middle school to cope and I still relapse occasionally. I just had to keep telling myself there was something I was living for and it would hurt the people around me. I learned that if I didn't talk, they would eventually give up. The days where we had a presentation or I knew I was going to have to participate, I was very anxious and always wanted to escape. **Brandy***

Participants described self-harming or self-destructive behaviours and they had suffered depression and experienced suicidal ideation in their past. They spoke about having to make their own coping and strengthening mechanisms to make it through the days, as in this example given by Decland:

*I remember a few times during high school where I had to make a quick stop to the bathroom, went inside the bathroom stall, cried for several minutes, wiped my tears, and went back out, pretending everything was ok. **Decland***

This participant also describes his depression, and its effects on feeling socially isolated from his peers, as he explains in the following statement:

*Getting by day to day is one of the hardest things in life. Struggling with depression as a result of not having any friends or any social life is something that have affected me since 13 years old. Playing sports definitely help to elevate my mood from bad to neutral, but sometimes it doesn't work because I'll still feel bad even after playing sports. **Decland***

5.3.4 Long Lasting memories

Although participants were all adults, who had been out of secondary school for over ten years they provided a vivid account of their recalled memories. As Decland states in the next exert how hurtful experiences were present in his memory. . He also describes that these are memories that will not easily be forgotten and can be retrieved:

And I remember so many events (not all, but many) that happened throughout my entire life down to smallest details such as the name of the person, the setting, which chair the person sits on, time of day, how that person made me feel, how I reacted, etc. Sometimes they (the memory) spontaneously come up to my mind when I'm staring at a distance while driving, lying down in bed, etc.

*I can pretty much remember almost everything I've been told by different people at different times, as long as the event hurts me (and almost everything hurts). I remember the "hurts", then I remember every little details (geographic location, time of day, who said what, who sit where, what I felt at that time, etc). **Decland***

Emma also describes something similar, remembering how distressing it was for her at the time:

*I remember a time when I was in primary school and the teacher asked me a questions but I couldn't answer her and she thought I was being rude, I still have memories of this time because of how upset it made me and how strict the teacher was. **Emma***

5.4. Family Experience

Participants wrote about their experiences with their family in the similar way their perceived not receiving the adequate support from school. Communication between school and family was perceived as important in terms of whether their SM was recognised and support would have been received when sought.

5.4.1. Lack of Recognition

Often some of the experiences relating to family were addressed by participants as they had communication to home from teachers on their report cards or at parent- teacher interviews. Decland describes the school report received by his parents:

*I got this note on my report card "Decland, when a teacher asks a question, you need to answer the question." I was 100% non-verbal at school. Literally could not say a single word for the entire day including when someone asked me a question." **Decland***

Participants also made references to teachers noticing something that was not as they expected, and telling their families. Participants reported that often because of the lack of information, no further action was taken and no one pursued further support for them. As Susan described:

*Teachers at primary school always told my mum I was quiet when they saw her, and that they were worried, but nobody tried to help me. At high school, I was given a meeting with one staff member whose job was student wellbeing, but nothing really happened with her either, just the one meeting were I didn't learn anything or get any tangible support. **Susan***

Olivia also explains that a lack of understanding of SM meant that the support needed was not received as teachers could not express what they saw to parents:

*The staff at my school were not knowledgeable about Selective Mutism, and neither was I. I think my life could have been a lot different growing up if I had received the support I needed. Because no one at my school knew anything about Selective Mutism, I had little to no support. **Olivia***

Participants also described limited understanding or recognition of the condition at home. They agreed that at times it may have been difficult for family to accept that something was a challenge, even though in some instances there was evidence of SM having effects on the participants' lives. For some participants, this resulted in SM being ignored and having an expectation to grow out of it, as Susan explain:

*My mum did nothing to help me despite my teachers telling her I was quiet. I didn't want to get help out of embarrassment anyway and I didn't feel like I could do anything about it. It was sort of ignored by myself and my family. I think I was expected to grow out of it. **Susan***

*My mom said it was "unacceptable" when my handwriting was not legible because of SM. She blamed me for not wanting to talk to a counsellor when I was a child. She was sometimes supportive but overall, I didn't get much help. My sisters didn't really comment on it a lot. **Brandy***

Other participants found comments that teachers made on their reports to be insensitive, and often misunderstood by parents and other family member to the extent of which they may be struggling with their SM. Emma explains:

*My family didn't react in a good way at all when the teachers kept saying to them that when I get stuck in class all I need to do is ask for help but what the teachers didn't get was that I wanted to ask for help I just couldn't ask for it and they never offered any help and support at all. **Emma***

Some participants acknowledged that family may not have been able to draw the connections to their challenges with SM because they were just the same happy outgoing person at home. They may not have realised how different they were at school or during other social activities, even though what teachers were saying was entirely different. Decland explained:

I don't think my family members have ever fully grasped the extent to which I was struggling to speak outside home because at home I was a chatterbox. They were told repeatedly by multiple teachers that I was extremely quiet at school, so they simply thought I was shy. I don't blame them, because if I were in their shoes it would be quite hard to imagine that this very loud kid at home is completely frozen at school." Decland

Participants described that professionals in some cases did not know what SM was. Decland expressed his frustrations in the following statement:

Also, getting my parents to believe that there is such a thing as Selective Mutism would have helped me tremendously. To this day, they have not fully grasped the extent of what it meant for someone to have this disorder versus being simply shy. Decland

She knew how I felt about professionals. We had been seeing them for years. I believed they were useless and had no more clue than someone who didn't have qualifications in child psychology. She was hoping for a miracle, I thought one day it will just disappear with age Edna

"My brother found it very frustrating in High School. He was five years older than me and he started to get many questions from students about why I was so quiet. He got very annoyed and embarrassed. Edna

5.5. Help Seeking

5.5.1. At school

Participants keep describing teachers' lack of understanding as having an effect on the process of seeking help or referring to support services. Emma explains:

*The teachers at primary and secondary school didn't pick up on my SM and all they kept saying that it's just shyness and I would grow out of it. **Emma***

Participants commented that they thought it would be helpful if teachers had known or been given training and resources on how to cope with students who may be having challenges because of SM. Susan describes that knowledge of SM may help to prevent some other ideas of social expectations, especially about speaking, as Susan describes:

*I also think teachers and other staff should be taught about this issue, so awareness is raised and they are given tips to deal with children with SM, as well as other mental health issues, so no ignorant comments are made or harmful actions undertaken (such as not letting me eat until I said 'please'). **Susan***

Participants found that they had received limited support, even though there were times when other staff or support staff were brought to work with them. Emma and Edna addressed this situation in the following manner:

*I didn't have any support from teachers in primary but they did have someone to come to have 1 on 1 session with me to help my confidence, the same sort of thing happened in secondary school as well but the teachers weren't very supportive. **Emma***

*I was placed on the SEN for High School (Special needs register). They did not tell me this, I noticed it while reading my end of year report.I told my friend in a class, and she shouted at Mrs ** (a woman who appeared at some lessons and sat with the class for no apparent reason) "Edna wants to know if she is on the special needs register?" The rest of the class were busy chatting so did not take much notice. Mrs *** looked a little awkward and approached me a few minutes later. She explained to me that I was on this register, and it was just to give teachers an understanding that if I found it difficult to talk, there is a reason and I should not get in trouble for it. I nodded, but was furious. They send someone to spy. **Edna***

5.5.2. University

Brandy, like most participants, spoke about the limited the support services throughout their education in all levels. In Brandy's case there was some awareness of SM, but still not enough support around SM existed. Brandy begins to explain this situation as follows:

*Counselling services in middle school was not helpful to me at all. I was not able to talk to them and I didn't get any kind of support in classes even though they thought I had SM. Counselling services in high school never contacted me or did anything. **Brandy***

Even when Brandy was at university, she found that she had a counsellor, who was not informed about SM and had to research it while in session, which broke down rapport. She relayed the following about her experience at university level:

*I had a counsellor in undergrad but he didn't understand SM and said I wasn't working hard enough. He turned his back on me in the middle of a session and started researching SM but by then he had already lost my trust. He kept touching my knee and my arm even though I would recoil and it clearly made me uncomfortable. **Brandy***

Brandy was the only participant who narrated in depth about her university experiences, though other participants did relay similar stories. Overall, disability services were showing signs of being helpful in some cases, but were met with resistance from university teaching staff, as Brandy explained:

*Disability services and counselling services in graduate school have been very helpful even though the teachers don't always listen. The Dean of Students was really horrible to me. He basically treated me like I was a criminal and forced me to sign a mandatory counselling form. **Brandy***

Participants explained how different the experience could be if in some cases there were opportunities for school staff to be more accommodating. As Olivia explains:

*University I think if people had been willing to be more accommodating it would have made a huge difference. I remember being distraught because I had no place to go, except for the noisy cafeteria where everyone stared at me. **Olivia***

5.5.3. Support Services

Participants expressed the need for appropriate support services for students with SM, as Emma stated:

*I think that there should have been more support put in place for my SM so that I could have coped better in both primary and secondary school. **Emma***

Susan explained further about the lack of information to support students. As Susan explained in the next statement:

*Teachers at primary school always told my mum I was quiet when they saw her, and that they were worried, but nobody tried to help me. At high school, I was given a meeting with one staff member whose job was student wellbeing, but nothing really happened with her either, just the one meeting were I didn't learn anything or get any tangible support. **Susan***

5.5.4. Other sources of support

Participants described receiving limited or no support until they were adults, and had to seek out their own support services or even therapy. They also described meeting practises that were not appropriate or aimed for another area of mental health, as Susan explains:

*I received no other support from teachers or other services until after I left school and got CBT on my own, although this was social anxiety based and not SM based like I was expecting. **Susan***

The process of receiving support from such services served was expressed by participants as only to further add to the frustrations for participants. If they were put in contact with other services often it was perceived as not helpful, or most of those services were seeing by them as unaware of what SM actually is or was. Decland and Edna stated:

*Support Services? Absolutely none. Every counsellor, psychologist, psychiatrist I have ever been in contact with has not the slightest clue what SM is. I would say the number of these professionals is between 15 – 20. I tried to be as articulate as I could be, but some of these so-called mental health professionals are still baffled by what I described. One psychologist tried to treat me with a technique usually used for a person with PTSD, despite my explanation on how I really didn't have PTSD. (Hell, no! I don't have PTSD!). **Decland***

*I imagined she and all the other professionals went home patting themselves on the back, because I eventually started to use a louder voice when answering their questions. The reality was I was simply just used to being in that room, in the same company, every week. I would step outside the clinic with my mother and go back to square one. There were various professionals thought childhood and teenage years. One doctor, called B*** and not Dr, tried the bullying tactic. He shouted if I nodded instead of talked. He criticized me if I answered "I don't know". This tactic appeared to work short term but did nothing, just like the gentle approach. These clinic appointments went on and just seemed to fizzle out at High School (age 11). **Edna***

Decland explained the challenges around receiving support or treatment for SM:

*Recognising that I wasn't simply shy is the biggest thing. (I was the opposite of shy at home). Then I could have received more help by professionals that were trained in this area. Unfortunately there is very few mental health professionals that have even heard of this, let alone trained to help. Another psychologist suspected that I had a mild Asperger's syndrome. Only after elaborate and exhausting explanation was I able to convince her that I don't have the slightest signs of Asperger's. It's very frustrating. **Decland***

5.6. Coping Mechanisms

5.6.1. Resilience

Participants all stated that they often had to find ways to make it through the days at school and even into adulthood where they found challenges. Some stating that they were at times able to deceive people into believing they were

just reserved or quiet. Decland describes this while having a conversation with a work colleague:

*Sometimes, I was able to “fool” people into believing that I never had this issue at all. After I shared my stories with a co-worker I trust his reply was “Decland, I thought you are on the outgoing side”. Or “I would never have guessed that you went through all this” or something similar. **Decland***

Participants talked about not contributing in class, or not answering questions even though they knew the answers. It was a challenge to stay in class that was not as passed with SM, as follows:

*I never put my hand up to answer a question even if I was 100% sure my answer was correct, It was having that fear of embarrassment, rejection and just being too nervous. So the couple of times I got asked my mind would just go blank ending up in me usually saying the wrong answer even if I knew it before I was asked. It’s like what was being talked about or what we were learning would disappear until the pressure was taken off me. **Taonga***

Participants mentioned how they made efforts to calculate the grades needed to achieve at school, or found a way around the need to be verbally participating. They often found that presentations and interactions with other students for assessment purposes to be the biggest challenges. Because of the challenges that SM adds, these efforts required preparation beyond what teachers may have realised. Decland described this situation:

*I would calculate my grade to know if I could avoid participation/presentations. I got one C but overall my grades were ok although I probably could’ve gotten straight A’s. My teachers were kind of rude about it and I was put into counselling. I was treated like a bad/stubborn kid. Some tried to understand and help but it never really helped me. **Decland***

Participants also talked about how, at times, they were left alone or ignored as teachers were not able to understand or support them. Taonga expresses her point of view:

*I think because they did just leave me to get on, I knew it was up to me to excel therefore pushing myself to do what was needed sometimes. I do often wonder if they had pushed me to do things, like have a talking part in one of the productions if it would of helped open me up or if it would of made everything worse. **Taonga***

5.6.2. Sports & extracurricular activities

Most participants talked about how sport played a role in their ability to cope, and/or to find reasons to go to school. Some participants described that in sports they felt they weren't expected to be anyone else, and often were seen as helpful to their team, and fulfilled leadership roles. Participants described the positive influences of their coaches who did not treat them any differently to other players. Olivia provided an example of her time with sport at school:

*I was athletic growing up, and was really good at soccer. I captained my high school soccer team and went on to play at the College level. I was only comfortable at school while on the soccer field or in gym class. Because I was so comfortable and confident on the pitch, sometimes I was able to speak. Although I never spoke much, at least it was something. Soccer season helped me because it gave me something to look forward to and a reason to go to school. **Olivia***

In the same manner, Decland, explained the helpful experiences of being involved in sports:

I did play sports, so it helped a bit. The teachers always made a comment to my parents when they picked up my report card at the end of every term/semester.

Decland

5.7. Participant Recommendations

Participants were given the opportunity to give their recommendations on what they think could have been helpful, or still could be helpful for them as adults. Participants spoke of the benefits of having the information made available and more prevalent, as Brandy explains:

*If teachers, counsellors, and school administrators were informed on this condition, I could've gotten help early on and maybe I wouldn't still be struggling with it today and feeling so much shame related to it. **Brandy***

Participants suggested that the information would also need to include ideas on how to work with a student in class who may be nonverbal or socially shy, as well as any other challenges that may be present in the classroom, as Susan states:

*also think teachers and other staff should be taught about this issue, so awareness is raised and they are given tips to deal with children with SM, as well as other mental health issues, so no ignorant comments are made or harmful actions undertaken (such as not letting me eat until I said 'please'). **Susan***

Brandy explains the need of support aligned to his experience:

....maybe if I had more support, I would be willing to go to counselling. If students were called out when they said things like "oh she talks", that really would have helped me. The shock just made me shut down again. I was always looked at like I was the problem and not my SM and that really needs to change.

Brandy

Participants also recommended that teachers be aware of not to assigning a negative labels or 'status' to students as it stays with the student no matter where they go. Participants often recalled being labelled or called something negative when they could not do as was expected of them. Participants suggested that this is something to be prevented to happen while in class and around the school in general, as Bandy illustrated:

*Teachers should not be treating any kid like they're just stubborn, especially if that kid has a mental health condition. Disability services in primary and secondary school should include people with mental illnesses because I think we are largely ignored and clearly that has negative effects. **Brandy***

Participants all made suggestions about ensuring correct support staff are available, or the ability to be referred is made available, as it would mean receiving immediate support. Though it is important to also receive the adequate

support and not be blocked into or be squeezed into services for other things. Susan and Emma both stated this need:

*I think more help should be offered in terms of support staff, and reviewing my behaviour over time to see if it has changed. If it hasn't changed over time, somebody should be brought in to help give child appropriate therapy to overcome the issue, with the parents' consent. **Susan***

*It would have been helpful to get help at school or at least be referred/recommended by my teachers to get help so I wouldn't still have SM as an adult. **Emma***

Decland described further that practitioners need to have a more first-hand experience or a clear understanding of what it means to be someone who lives with the effects of SM every day. He explains:

*I think the best person to help with children with Selective Mutism IS NOT mental health professionals. I think the best resource and moral supports for these children are former first-hand sufferers like myself who can actually empathise, NOT someone who has a PhD/Master's in Psychology/Counselling/Speech Therapy but have never experienced it themselves. **Decland***

In this chapter the findings of the study were presented. Participants described how they had been diagnosed or had identified as being someone living with SM. Participants also told their stories of educational and academic experiences and the support received during their time in education. Participants' narratives also transpired into themes rich of their emotional experiences. They also talked about some of the other mental health challenges they had faced. Participants discussed family experiences and the manners in which support were sought and received and provided examples in which the educational system was limited to attending their needs. Some of the last themes emerged from participant's stories of how they had their own coping mechanisms. These themes were followed by the participants' recommendations derived from their experiences with SM.

Chapter 6: Discussion

This study applied a qualitative research methodology to collect and analyse the participants' stories about living with SM during their educational years. The results indicated that adults with SM have rich narratives that were organized within salient themes. The themes that emerged from the data will be discussed in this chapter. As described in the previous chapter, these themes are: diagnosis and identification of SM, education, support services and treatment, assumptions and stigma, strengths and limitations and an introduction of the Selective Mutism Spectrum (SMS).

The participant's narratives offered insights into the reality of their lives and experiences as well as their perspectives of themselves as students, their educators and health care professionals.

6.1. Diagnosis & Identification of SM

Adults who identify as having SM have often been considered shy or different by peers, teachers and family and it is commonly assumed they simply grow out of it. Selective Mutism however may have more lasting effects if not acknowledged or left without appropriate support. Viana, Beidel and Rabian (2009) suggested that in the last fifteen years, research and publications on this topic are limited. In this study, early studies and reviews on the topic were key aspects in clarifying important aspects relating to SM including its assessment and treatment.

The formal diagnosis of SM appears not as frequently done as with other disorders, even though it is included in the DSM V under anxiety disorders. The DSM V defines SM as an inability to speak effectively in specific social situations. Selective Mutism is associated with significant impairment that last more than a month and is not affected because of language barriers or any other developmental disorder (Chavira et al., 2007). Though participants in this research were not all formally diagnosed and faced challenges finding out about what SM is. Participants described their frustration facing the lack of diagnosis, as there is not a clear identified cause of SM and the disorder may be better conceptualized as arising from the interaction of various environmental and genetic factors. Existing literature suggests that further research needs to be done to be able to

understand SM further. Cohan et al. (2006) has also suggested that SM is more prevalent when children start school, as it is often the first point of contact, where diagnosis or support implication could be vital. However, there is limited evidence that the use of speech interferes with education or occupational achievement, or with social communications. If underdiagnosed and left unsupported, SM becomes more difficult to manage. Associated features of SM that can also be identified include excessive shyness, fear of social embarrassment, social isolation and withdrawal, clinging, compulsive traits, negativism, and temper tantrums as mannerisms to cope with the stress (Cohan et al., 2006). These authors have further explained that though diagnosis has improved over the last decades, and some support has happened for some people living with SM, it has not necessarily changed SM ideas or how this it approached, finding that some adolescents with SM today had, at times, received support but with limited therapeutic success. Further to this Sutton and Forrester (2016) state that though diagnosis and intervention rates are currently improving, adults with SM are significantly less likely to be diagnosed or receive help as children. If SM persists for a prolonged period, there can be serious mental health repercussions, such as depression, social anxiety, generalized anxiety disorder, which participants in the research made connections to (Sutton & Forrester, 2016).

Through the presentation of participant's accounts and the exploration of their own diagnosis (or lack of), is supported by literature which indicates that SM is commonly not well understood and there are aspects of this condition that needs further research, especially in areas addressing adequate and available support practices for SM sufferers. The unclear indications of the prevalence of SM in adolescents and adults also needs further exploration. The inability to establish the prevalence of SM s limited by the lack of a comprehensive and consistent theory about integrating etiology, assessment and treatment of SM (Viana et al., 2009).

The following sections discuss the role that education played in the participants' experiences and including the challenges described by them living with SM during this period of their lives.

6.2. Education

For participants, the classroom was the setting in which their lack of speech became most noticeable and problematic due to the academic and social expectations. This has also been addressed by previous literature (Shriver, Segool, & Gortmaker, 2011). Participants described that they encountered for the first time perhaps the experience of being different as they found speaking a daily challenge, whether it was answering to the roll or having to ask for help when completing class tasks. Often, participants remembered that their teachers were the first adults to notice or say something about their difficulties with speaking in school or during tasks.

Cleave (2009) states that a teacher may be the first person to identify the full extent of SM in a particular student, when they are presented with cultural expectations about communication styles within their school. A student with SM may show signs of persistent shyness and can be perceived as being rude and defiant, as described by participants in this research. There are suggestions that children with SM can appear timid and anxious, but in a dynamic manner, it can also be interpreted by teachers as being controlling and manipulative. Participants spoke to their teachers often not knowing about SM or knowing how they could support students with their schooling or to refer them to other support services. Participants suggested that teachers could receive further education to make a distinction between children who have an inability to communicate, due to physical or learning difficulties, and children who are able to communicate in particular settings. It is suggested that children' refusal to speak in school or certain social situations can be misinterpreted as wilful defiance and a threat to a teacher's authority (Cleave, 2009).

According to the participants' accounts education was not always a positive experience. Often participants spoke of the lack of information that their teachers had about SM, or lack of support from other potential support services. The emphasis on language within the education curriculum, the cultural expectations for communication, the allowances teachers make for "shy" children, and the historical perspective of SM, are factors adding complexity to the difficulties in working with a student with SM within a school and classroom settings. These factors, coupled with the assumption that few teachers will have experienced

working with a child with SM previously, can make a teacher feel incredibly isolated (Cleave, 2009).

Participants also talked about how family did not always realise how different they were between school and home because they talked at home, but not always at school, if at all. Participants spoke about feeling self-conscious and ashamed of being mute. This subjective experience in people with SM has been suggested by Sutton and Forrester (2016). This experience is common for children with SM who usually speak at home but are mute in other situations, such as school. There are many assumptions made about children with SM, including that they have been traumatized or are simply stubborn (Trainor, 2016). Participants spoke about encountering a variety of conjectures about the reasons behind not able to speak when required, and reported that this was often not helpful. Although some participants reported that they were not directly bullied, they felt sometimes ignored or felt as if they would be forgotten, and even at times told they would not succeed any further until they were able to speak.

It is important to consider that despite the seemingly low incidence of studies about SM in research, mute behaviour has a powerful effect on teachers. However, in spite of the powerful impact of this condition on the person and others, no specific studies on teachers' perceptions have been conducted. Further studies on the experiences of teachers dealing with SM in their classrooms may include the exploration of emotions such as anger, confusion, frustration and helplessness. The recognition of these feelings, linked with the probability that they may have not previously taught a student with SM, may lead to them seeking support from outside agencies. Participants recalled some teachers sending notes on report cards to their parents, as a manner of communicate and move forward. This strategy was found to be ineffectual by the participants as there was still not enough information about how to work and provide for a student with SM in the educational setting.

Cleave (2009) also suggests that the higher prevalence of school-based identification of SM, rather than a clinical based identification, is due to the identification of children with undiagnosed SM or those who have not been referred to health or other social support services. It may also be suggested that teachers and school nurses may be unsure when to refer to any other services,

especially as students with SM are typically not disruptive in class. Participants described that because their teachers did not know enough about SM, they did not refer themselves to school support or to any other services. Often it also meant they could not name it to their parents or be able to give any advice to parents as to what they thought were possible supports that could have been put in place.

6.3. Support Services and treatments

Participants suggested in their narratives that earlier intervention would be helpful, especially at an earlier age, to ensure that the condition does not persist in the same manner into adolescence or adult development. As Trainor (2016) states, early intervention with children suffering with SM are crucial, the longer SM remains untreated, the more difficult it is to treat. Adolescents with SM have already lived silent lives, and thought they have to cope with this. As addressed earlier in the literature, these children frequently have few friends, finding that being the silent friend is not an easy position, and also dealing with the anxiety provoked by speaking as a potential way to draw attention to them (Trainor, 2016).

In some cases, practitioners have suggested that behavioural interventions are an effective treatment for SM. Interventions are often planned with a combination of behavioural strategies, such as contingency management, shaping, stimulus fading, systematic desensitization, and self-modelling. Cognitive behavioural interventions typically used for treating anxiety disorders appear to be successful for SM, although the evidence is not necessarily conclusive (Viana et al., 2009). Participants in this study, described this therapeutic method as effective in providing some relief, but was described as not enough as the sessions had ended before the condition was considered resolved. The frequency of intervention, however could also be attributed to the lack of available, adequate treatments that are specifically set to address SM and the effects of living with SM (Sutton & Forrester, 2016). There were examples when health practitioners were sought for advice and one health professional responded not having experience of working with SM before, therefore they could not help. For adults, there seems to appear to be no help available and in some cases with adolescents. Participants in this study found that when they sought support or therapy, the

practitioner appears to have vague ideas on how to treat SM or understanding the condition. Participants recalled that when support was sought there were a tendency to refer them into other mental health areas, as the differential diagnosis is difficult in SM cases. The influence of the psychodynamic conceptualization of SM has contributed to SM to be seen as more influenced by anxiety, and investigations in this topic have decreased in the last two decades (Cohan et al., 2006).

When SM is assessed as an anxiety driven condition meant that much of what was applied for support was limited to anxiety, since the lack of speech was a part of the co – morbidity of SM. This aspect was seen by the participants in this study as not helpful to the successful treatment of this condition. It was suggested by participants, that it may be more beneficial for people affected by SM that more effective support may be provided by other sufferers, regardless of the age in which they were affected. These remarks suggested that younger children would benefit from what older people with SM would have to say about supporting someone living with SM (Oerbeck et al., 2014). This strategy would address some of the existing assumptions and ideas that educators and practitioner have of SM.

Some of the results from a study of non-referred children with SM has suggested that although some improvement may occur almost spontaneously, the majority of sufferers would remain symptomatic for long periods through their life span. It has been suggested that early intervention may be especially important (Cohan, Chavira, Stein, 2006). Some participants talked about some early identification being made by support staff or teachers, and but found that no further support was received as a result of this. Even after an intervention, participants with SM reported still facing challenges to overcome, suggesting that interventions and support need to be ongoing and over a prolonged period of time.

6.4. Assumptions and stigma

Participants described the stigma they encountered throughout their education, and into their adult life. Stigmatizing can be described as a multidimensional process, in the sense that it touches on the identification of several different forms of social differences. As a concept it can be combined with

an interlocking system of oppression, or control of an individual within a society (Jensen, 2011). Participants spoke about how they had experienced some form of stigmatization by students, teachers, families and staff members. They remembered for instance being called names, and at times, feelings bullied because they did not speak as was expected in certain social situations.

Assumptions were frequently made by others seeing SM being as a choice, were described by participants. Sutton and Forrester (2016) suggested that it can be assumed that someone with SM has some version of control over what is happening when SM is present. While it may appear on the surface that they are in control and are choosing when and where to speak, it is an involuntary response rather than being deliberately silent in certain situations. This has also led to students or individuals being considered oppositional, deviant, stubborn or rude as they do not meet the expectative of speaking in specific social situations.

The participants' narratives indicated that SM eventually grows to be a part of the sufferer and is not a choice. It is a condition in which anxiety can play a role, being only a component of the complexity of the condition. People with SM have learned to live with, and some have come to understand that they may live with for as long as they live, even though it does not define them (Sutton, & Forrester, 2016). Although social isolation seems to improve into adulthood, many relationships seem as if they may not take a permanent hold in their lives. Authors have described the subjective experience of person with SM. They feel overwhelmingly isolated, trapped, scrutinized, and humiliated by their inability to speak, and absolutely barred from the ordinary things in life, like forming friendships and having their own families (Sutton & Forrester, 2016). Often much of the shame and humiliation that sufferers have felt was during school years, followed them into adulthood.

In accord with what has been described in the literature of SM, participants in this study depicted experiences of feeling patronized, discussed and teased when being referred to by their peers and teachers, or simply ignored by them. These experiences made them to feel stigmatized. Most were unsure what to do with feeling isolated and misunderstood, often participants described finding other areas to cope such as playing sports or spending time in the library. The idea of identity formation is inherent in the concept of being 'othered', and assumes that

people seen as secondary, are at times relegated to certain positions and perceived as deviants within a given discourse. It is in this process that a student with SM is made the other and is construed as inferior (Jensen, 2011).

It has been argued that the institution of school is a place and a space where notions of academic success are embedded within the values and beliefs of a specified agenda. Educational strategies, testing, and curricular activities, dictate how students make sense of their academic identities, and expose students to the norms, including values, and the hegemonic ideology of the larger society, and their place within this society (Borrero, Yeh, Cruz, & Suda, 2012). Due to the strength and endurance of these definitions of what it means to be a student, youth quickly learns the extent to which they belong within this system (Borrero et al., 2012). Participants in this study, identified knowing they were different, finding their difference not easily accepted, and having many others deciding on their academic capabilities. This included assumptions about their capability in being able to complete academic achievements, as some of them were often told they could not continue until they learnt to speak. Assumptions were made from other students who spoke down to them as sufferers.

Children with SM were often branded as showing oppositional and passive aggressive behaviours and it was believed to be the reason why they have SM. However, more recent literature does not necessarily support this view. As Cleave (2009) highlighted typically practitioners judge Oppositional Defiance Disorder (ODD) as a common diagnosis among their selectively mute clients. Parents of selectively mute children have limited information on the differences between ODD, Attention Deficit Disorder (ADD) or Conduct Disorder [CD], as the diagnosis criteria for these disorders is usually confounded, limiting the clarity for differential diagnosis (Cleave, 2009).

It can be suggested that the interpreted oppositional symptoms, can be seen as coping (secondary) mechanisms to avoid anxiety-provoking situations, rather than symptoms of a primary behaviour disorder. Also that both anxious and oppositional behaviours may exist in the same affected person, and it can be noted that parents of children with SM have reported difficulties with their social cooperation, responsibility and control, but that the symptoms were not severe

enough to warrant a diagnosis of ADD, ODD, or CD. It seems that, in children with SM, oppositional factors are less common than anxiety factors (Cleave, 2009).

6.5. Strengths and limitations of research

This research utilised a qualitative approach as a methodology to address the topic of the experience of people living with SM during their educational years. Although reliability and validity have traditionally been associated with quantitative research, there are also important concepts in qualitative research. Examining the data for reliability and validity assesses both the objectivity and credibility of the research. The data provided by participants in this study are rich in contextual and personal narratives. These retrospective narratives shaped much of who the participants are today. This research presented a possibility of bias, since the researcher has a personal experience with SM as well as having encountered other people enduring the same condition, however, the data was explored with an open disposition and the analysis was done with the support of the researcher's supervisors, as a manner to maintain the reliability of the results.

Participants in this study were individuals who had lived with the effects of SM, from childhood into adulthood. Individual face to face interviews are typically challenging and anxiety inducing situations. An open-ended online questionnaire was chosen in order to give the participants more freedom of expression, however these type of questionnaires are not the most common of methodologies used in the research of SM. Further studies are needed on SM utilizing different methodologies specifically chosen to fit the needs of participants in ways that consider the impact of research methods on participants with SM.

The research presented made use of a small number of participants, however, this is due to these participants completing the questionnaire before the closing date. Overall there were over thirty enquiries, though many stated that the time limit created pressure making it difficult to not be anxious when trying to complete the questionnaires. The small amount of participants meant that the narratives were detailed and rich in the end, allowing for strong data. As participants also gave accounts of different educational systems, the differences

were considered even though the themes from participants' narratives were able to have similar themes regardless of educational system or locations.

Considering how SM is presented within the literature or how little recent literature there is, it can be suggested that further research is needed on the topic of SM to support areas of knowledge such as the identification of frequencies of occurrence the effects of SM in daily life, the effects on development, and the effects of education, and gender factors mediating the condition among other aspects. This may require designing longitudinal studies tracking the trajectories of the condition and understanding how it changes from age to age, and in which ways it affects development. The studies need to integrate qualitative and quantitative data.

There is some consensus within the research that a major factor in the etiology of SM the presentation of anxiety though it had been placed under other anxiety disorders categories for decades before the new DSM V changes (Cleave, 2009). However, there seem to be some groups of children with SM who may not suffer with a social phobia but who may have a specific phobia of expressive speech, and in other group of children SM -occurs with compromised language, cognitive or motor abilities. Selective Mutism could actually conceal potential developmental difficulties. To consider a multi-faceted model of SM, seems to be a more accurate approach to understand this condition, with particular factors playing a role in each individual case. The importance of considering a range of hypotheses is essential in order to be able to suggest individualised interventions for each child with SM (Cleave, 2009). This idea, led this study towards the development of a spectrum that may contribute to the identification of SM within a classroom and early diagnosis by appropriate services.

Criteria for diagnosis need to be able to match with, not only SM, but with other occurrences of co – morbidity, already included in the DSM V such as Autism Spectrum Disorder (ASD) and Auditory Processing Disorder, conditions that can coexist with other learning disabilities. Part of a differential diagnosis of SM needs to happen under a new paradigm or innovative tools to make easier and simpler the identification of SA for teachers and other staff so they can refer the sufferers to the adequate support. This would mean that new trends in diagnosis need to be created, rather than be prescribed to an older paradigm for diagnosis and

treatment. Adding to these tools there is a need for further studies along with developmental perspectives that may translate in practices specifically designed to address SM and its co – morbidity, rather than trying to make an existing model fit where it does not.

As defined previously, SM is manifests as a limitation to speak in specific social situation. Lack of speech that is better accounted for by another psychiatric, neurological or physical disorder is also not considered to be SM. The latter criterion is sometimes problematic, since pervasive developmental disorders and communication disorders may either mimic SM or occur together with SM, making it difficult to decide on a primary diagnosis (Manassis, 2009).

6.6. Selective Mutism Spectrum (SMS)

The data that gathered from the participants' narratives as answers to the questionnaire offered an overview of the manner in which they had experienced SM. All of them were capable to be academically successful even though they experienced judgement. Some reported currently feeling the effects SM has on their lives, while others were able to become employed or to complete their studies. All participants could identify the possibility of experiencing some other deeply emotional experiences. If looking through the data from a larger overview, then some participants would be on one end of an spectrum where some had grown with SM but were doing well, and some that were in the middle with some effect but still having successes socially and others, like one participant expressed, would be at the extreme of this spectrum, (with untreated condition and still experienced the challenges SM in their life every day). For the purpose of understanding this range of outcomes, a spectrum model has been outlined within the context of this study (Fig. 1)

As stated before, many previous literature studies on SM relied on chart reviews to locate diagnosis and standardised structured assessments were uncommon (Viana et al., 2009). Selective Mutism, however, has a variety of effects on participant's lives, and could be placed onto a spectrum allowing to describe SM as a fluid and dynamic occurrence throughout life. This spectrum goes from high occurrence of SM with overall inhibited life function, though

educational opportunities and employment opportunities, and social development being stilted as well.

A medium SM occurrence implies educationally, socially and employability is more possible, but SM can still affect its sufferers. The low SM occurrence side implies that people with SM have the challenges added by SM but are fundamentally able to adjust to life as time moves on and with intervention. The same spectrum can also be used to identify at which point someone's age or development SM could be occurring. Participants, overall, were able to identify long term effects from a young age even though not diagnosed, and later self-identified themselves as either teenagers or adults. Selective Mutism had typically being identified by some participants as a part of other diagnoses, or a co-morbidity of them. The spectrum model developed in this research may aids the identification and inclusion of other diagnoses occurring alongside SM.

When looking at the participants questionnaires from a wider view, while considering and including the information that they had provided in their narratives, it shows that SM occurs differently for all participants. The spectrum can be viewed from a high occurrence of SM meaning overall inhibited life function, limited educational opportunities and limited employment opportunities, with social development being compromised as well. This is followed by medium occurrence of SM, where students or someone living with SM can do some tasks more easily while still facing challenges. A medium SM occurrence indicates that although educationally, socially and employability for the individual is possible, as they can manage the effects of SM better, SM can still hold powerful effects in the person's life. The other end of the spectrum is the low occurrence, meaning that though someone may from time to time have challenges, SM is not as difficult to cope with, and it is easier to learn to address and cope with some of the effects from it. A person on the low SM occurrence has fundamentally being able to adjust to life as time moves on and with the help of an intervention.

Selective Mutism has also been identified by participants to, at times, come with other diagnosis, or a co – morbidity, which on the spectrum model, has been extended to include the possibility of other diagnoses that could occur alongside SM. However, the etiology of SM is not well understood due to the heterogeneous presentation of the disorder, and the fact that it appears to be influenced by many factors including, genetics, temperament, psychological well-being, attainment of developmental milestones and social factors makes more difficult its identification (Nowakowska et al, 2009).

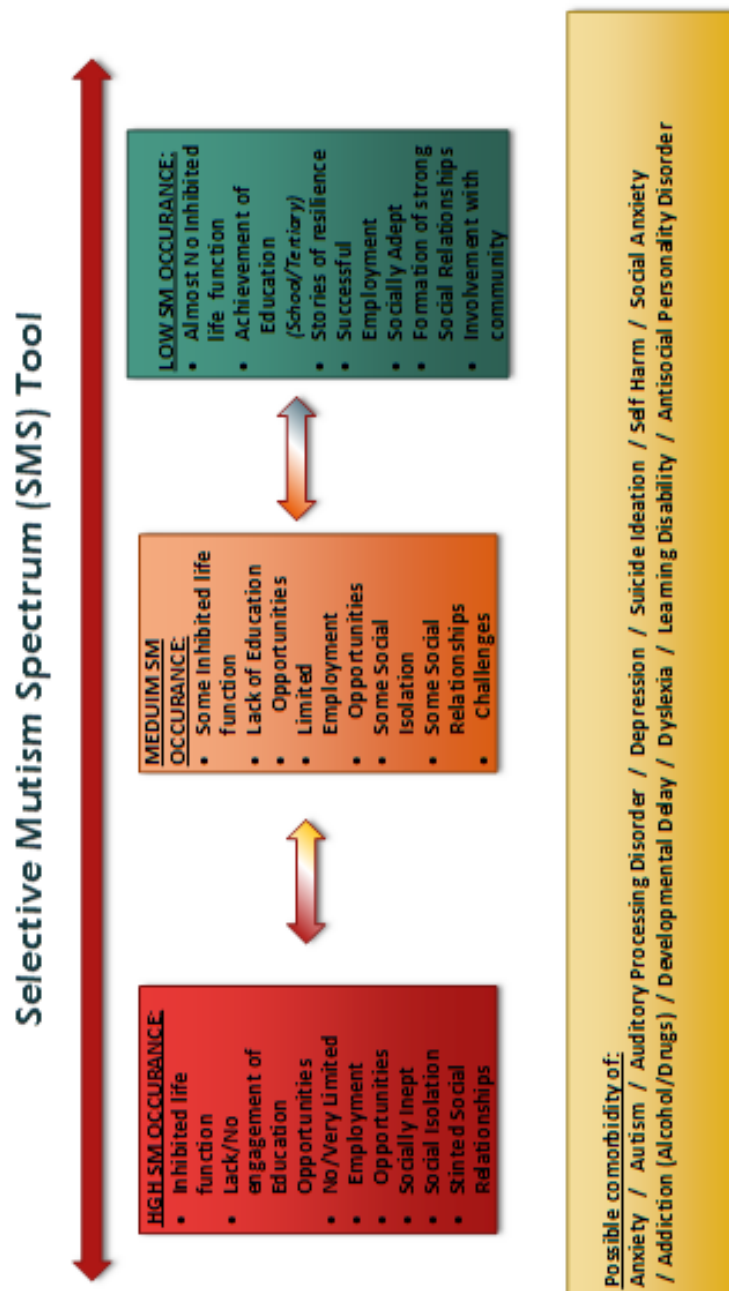


Fig 1: Selective Mutism Spectrum (SMS)

Selective Mutism is frequently first recognized at school and added extra challenges to surviving school and social experiences. Though all participants had negative experiences, overall none were presented intellectual challenges. Although in some cases, they stated to be emotionally behind their peers, factors that were identified by their teachers. Selective Mutism however, seems to have a range of degrees and effects on the participant's lives, and for this reason a suggested spectrum was suggested within the context of this research (*Fig.1*).

6.7. Recommendations

Although SM etiology and treatment has been attempted to explain from different theoretical perspectives such as psychodynamic, behavioural, family system, trauma-related, and genetic predisposition, accumulated findings suggest that the current determined views of SM are still inadequate. It is likely that SM could be the result of complex individual– environment interactions occurring at multiple levels over time (Viana et al., 2009). Considering this, it can be suggested that further research is needed on the topic of SM to support areas of knowledge such as the identification of frequencies of occurrence the effects of SM in daily life, the effects on development, and the effects of education, and gender factors mediating the condition among other aspects. This may require designing longitudinal studies tracking the trajectories of the condition and understanding how it changes from age to age, and in which ways it affects development. The studies need to integrate qualitative and quantitative data.

The learning environment for students living with SM needs to include various types of learning which can complement each other. Blending the formal learning that takes place in a typical educational classroom, which is known to lead to diplomas and qualifications, with informal learning processes that are not necessarily intentional and can occur naturally in everyday practice, learning and life, would make educational achievement for a student with SM more attainable (Illiers, 2009). In order to make sense of the diverse nature in which SM is presented, this research also introduce a Selective Mutism Spectrum (SMS) as a tool that could be used to identify the variability of functioning for people experiencing SM. This spectrum could also aid to identify if there are any co – morbidities alongside SM. This spectrum could support school staff or practitioners to distinguish whether someone with SM is made progress or if

change has occurred. Though this tool will need further development in the future.

Chapter 7: Conclusion

Research on the topic of SM presents many challenges, not only because SM does not have a long history, but because of the manner in which the condition has been shaped and understood over the last several decades. Moving from the idea of being elective, to becoming selective, and moving from the idea of choosing not to speak, to finding that anxiety could play a larger part in this.

The research presented here, aimed to explore the experiences of those who had lived, grown up and learnt to live with the effects of SM for most of their lives. Participants were asked to reflect and narrate stories about their experiences through education, the way they felt, the support they received, how their families reacted, and also give recommendations. The qualitative exploratory research methodology allowed the participants to tell the stories from their own perspectives, and contribute with new ideas that may contrast previous views when talking about SM.

Participants generated rich data in the form of stories of resilience, memories of what their education was like, and differing accounts for their lived experiences with SM. While most participants had found challenges in school, and still did in life, there were some that reported being less affected. Themes of diagnosis and how participants had experienced education throughout different developmental moments and further themes of bullying, stigma, mental health, seeking support and stories of resilience were present. Participants described narratives from starting school right through to adulthood. Participants also spoke about the challenges in finding good support or intervention, and having to find this later as adults after identifying SM for themselves.

Participants highlighted the lack of knowledge around their condition including that their families often did not know or understand and, what their teachers meant when they were referred to as “quiet”. For participants, school was a significant challenge, with many events that have stayed etched in their memories, for life. Participants’ made recommendations for what they thought could have been done for themselves and for others moving forward.

In order to make sense of the diverse nature in which SM is presented, this research also introduces a Selective Mutism Spectrum (SMS) as a tool that could be used to identify the variability of functioning for people experiencing SM. This spectrum could also aid to identify if there are any co-morbidities alongside SM. This spectrum could support school staff or practitioners to distinguish whether someone with SM is made progress or if change has occurred. Through this study, recommendations can be made for information about SM to become more available and for further research for SM and those living with the challenges that SM presents.

There are limitations and challenges of this research that lead to the need for further, more in-depth investigations into particular aspects of SM in order to gain further understanding of the condition. These aspects may include how and why SM occurs, and what factors contribute to its identification, diagnosis and treatment. Further research on the topic could lead to tailored specific treatments to support people living the effects of selective mutism.

7.1. Participant Recommendations

Participants made recommendations about what could have been done to improve their lives and treat their condition. For instance, participants suggested that a person affected by SM could contribute to the further growth into the development of treatments for SM as it could be done by someone who has already lived with SM. This would make it easier to gain an understanding toward what this means to live with this condition.

It is important to make the information available in all areas, not just education, and that it is important that teachers are given clearer strategies of how to work with a student in class who may be living with the effects of SM. Participants wanted support services to become more available at younger ages, and some suggested that had this happened for them it may have changed how SM had continued to affect them throughout life.

The aim of this research was to qualitatively explore the narratives of adults living with SM, but also aimed at raising the awareness of SM as being more than an unusual childhood disorder. It seems that the involvement and the account of adults who have lived with SM for a prolonged period, may make it easier for

other experiencing SM to generate ideas or ways of navigate the condition rather than only seeing SM from a psychopathological approach based only in a clinical diagnosis criteria.

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Appendices

Appendix 1: Facebook Post Poster

Seeking Brave Selectively Mute Research Participants

A study is being done by a New Zealand Masters student at Whitireia. This study will be focussing on Adults with Selective mutism and how the experience of school and life from your perspectives.

But.....we need your help to tell your stories.

Information will be collected via an anonymous questionnaire. You will be asked to tell your story about what it means to be an adult with Selective Mutism in depth and given the opportunity to present how school was for you and how life or work is now.

Questionnaires, information sheets and consent forms will be sent out from mid-October.

If you are interested in being a part of the study and telling your story, and helping to create information about Selective Mutism, mostly as adults, please make contact by:

Emailing izzynz@gmail.com

Or

Texting 0223508005



Appendix 2: Facebook Post Message

Hello,

I am a Whitireia postgraduate student in New Zealand who is working on completing my Masters Thesis which is a study of Adults with Selective Mutism (SM) and the impact of their school experiences.

I will be collecting information via a questionnaire document with questions that allow you to tell your perspectives and stories about what it means to be an adult with SM, how school was for you, and whether you got the support you think was needed during your schooling and after.

If you are interested in being a part of the study, and telling your story, and helping to create information about SM, mostly as adults or young adults, please contact me below by posting a comment.

Participation is entirely voluntary. All information collected will be completely confidential.

It's the chance for you to tell your stories.

Please feel to contact me directly on izzynz@gmail.com or on the Facebook messenger.

Or leave a comment and I'll get back to you.

Appendix 3: Messenger Response to interest

Thanks for your interest in taking part in my thesis research.

I have attached the information sheet and questionnaire, which includes the consent form.

Once you have read the information sheet and feel you understand and am happy to continue, feel free to begin the questionnaire after ticking the consent box.

You are free to write as much as you like and in as much detail as you like.

I am available on messenger if you have any further questions.

Appendix 4: Participant Information Sheet



The lived experience of Selectively Mute Adults while at school

Thank you for your interest in this research project. This information is provided so that you can make an informed decision about participating in this study.

This project is being undertaken by Isedora Lewis and has been approved by the Ethics and Research Committee.

What is the purpose of the project?

The research is aimed to explore *the lived experience of Selectively Mute Adults while in education*, with the intention of gaining strong nga korero (stories) that speak to the differing perspectives of living with Selective Mutism growing up. The nga korero collected aims to explore the lived experiences through stories that are told by the participant about being SM while in education that will add differing perspectives to what teachers already know about Selective Mutism.

What type of participant are we looking for?

The types of kaiuru (participants) that will be asked to volunteer are adults (above the age of 18) and have been identified as Selective Mute either by diagnosis or by self diagnosis. There are no restrictions on any cultural or ethnic identity, or takenga (origin). We ask that you not be in current psychiatric care. If you choose to volunteer, you will be asked to tell your nga korero of your past experiences of living with of Selective Mutism.

What are the possible benefits and risks of participation?

The benefits of being a part of this research is that you will be helping to create and add to the knowledge about adults with Selective Mutism and their experiences of education, which could affect how and when others receives support or changes that way that being Selectively Mute is viewed.

There are no intended direct risks in participation to you. If for whatever reason completing the questionnaire causes you feel upset, moved or stressed, the following numbers provided are available for you to use to gain support if you feel you need it.

Selective Mutism and Anxiety Service Contacts

International	
VOICE voice@selectivemutism.org.nz http://selectivemutism.org.nz/	Selective Mutism Foundation SUE NEWMAN Selective Mutism Foundation, Inc. P. O. Box 25972 Tamarac, FL 33320 http://www.selectivemutismfoundation.org/
Selective Mutism Foundation SUE NEWMAN Selective Mutism Foundation, Inc. P. O. Box 25972 Tamarac, FL 33320 http://www.selectivemutismfoundation.org/	Selective Mutism Association (SMA) info@selectivemutism.org https://www.selectivemutism.org/

<p><i>ispeak: A voice for people with selective mutism</i></p> <p>http://www.ispeak.org.uk/Default.aspx</p>	
<p><i>Selective Mutism Network</i> (407) 242-6040 forms@selectivemutismnetwork.org http://www.selectivemutismnetwork.org/</p>	
Canada	
<p><i>Call 1-800-SUICIDE (1-800-784-2433)</i></p> <p>To get help right away, any time of day or night. It's a free call.</p>	<p><i>Your Local Crisis Line:</i></p> <p>310-6789 (do not add 604, 778 or 250 before the number) 24 hours a day to connect to a BC crisis line, without a wait or busy signal. The crisis lines linked in through 310-6789 have received advanced training in mental health challenges and services by members of the BC Partners for Mental Health and Addictions Information.</p>
<p><i>HealthLink BC:</i> Call 811 or visit www.healthlinkbc.ca to access free, non-emergency health information for anyone in your family, including mental health and substance use information. Through 811, you can also speak to a registered nurse about symptoms you're worried about, or talk with a pharmacist about medication questions.</p>	
United Kingdom	
<p><i>Anxiety UK</i></p> <p>Anxiety UK Zion Community Resource Centre 339 Stretford Road, Hulme, Manchester M15 4ZY Tel: 08444 775 774* (open Monday to Friday 9.30- 6.00) Admin/office line: 0161 226 7727 Text Service: 07537 416 905 Infoline: 08444 775 774* Mon-Fri 9:30am - 5.30pm</p>	<p>Music therapy Lambeth</p> <p>http://www.musictherapylambeth.org</p>

support@anxietyuk.org.uk services@anxietyuk.org.uk https://www.anxietyuk.org.uk/	
Australia	
Selective Mutism Clinic, Sydney Selective Mutism Clinic Suite 301, Level 3, 118 Christie St St Leonards NSW 2065 Phone: 0405 430 530 admin@selectivemutism.com.au https://selectivemutism.com.au/	Therapies for kids Therapies for Kids 37 Nelson St Annandale, NSW2038 Australia PH: (02) 9519 0966 Fax: (02) 9519 3766 http://www.therapiesforkids.com.au/
Dr. Elizabeth Woodcock and Associates Clinical Psychologists, Sydney Suite 301 Level 3 118 Christie Street in St Leonards Sydney 0405 430 530 elizabeth@woodcockpsychology.com.au http://www.woodcockpsychology.com.au/	
South Africa	
Childpsych, South Africa http://www.childpsych.co.za/	Cape Town Anel Annandale Email: anel@www.childpsych.co.za Office: 021 423 0739 Mobile: 082 695 9319 Physical Address: Firdale Wellness Cen Firdale Avenue, Gardens.
Overberg Lianna Morrison E-mail: Morrison.lianna@gmail.com Office number: 028 313 1669 Physical address: 4 Magnolia Street, Hermanus (Overberg Therapy Centre)	Johannesburg North Orit Grossman Email: orit@psycho-dynamic.co.za Mobile: 083 350 2628 1 Streatham Crescent, Bryanston
Johannesburg East Melanie Hartgill Email: shrinkproof@mweb.co.za Office: 011 640 4498 or	Johannesburg West Jenny da Silva Email: jennysilva.edpsych@gmail.com Mobile: 082 777 4768 Lifesyle Garden and Home Centre,

Mobile: 082 678 4300 7 Tenth Street, Orange Grove, Johannesburg	C/O Beyers Naude Drive and Ysterhout Avenue, Randpark Ridge
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What will participants be asked to do?

As a kaiuru (participant) you will be provided with this information sheet and a consent form to read and sign, then to return. Once this is completed you will be supplied with the questionnaire sheet via email.

The questionnaire will ask you questions relating to yourself as a Selective Mute, what it was like going to kura (school) and what it was like when Selective Mutism was present the most. You will be asked to be as honest as possible, and to include as much detail as you would like, including both positive and negative stories.

Can participants change their mind and withdraw from the project?

You can withdraw from the project at any time. No reason is needed if you choose to withdraw. There will be no disadvantages to you of any kind, or any consequences.

What information will be collected and what use will be made of it?

The questionnaires containing your nga korero (stories) will be collected and analyzed to look for similar ideas, experience, themes and any other information that gives the story strength. The data will be presented in the forms of case studies which all personal details have been changed to ensure your confidentiality.

These will be presented as a report which you can request a copy of, and also to be part of presentations that are made on the research and date which you are a part of.

Will the information remain confidential and anonymous, and how will this be done?

All information will be kept strictly confidential with the researcher and no names will be used in the collation of the data. When the results are published you will not be personally identified. Any information provided by you can be viewed at any time.

Is there a cost of taking part?

It will not cost you anything to take part in this study, just time and reflection.

What if I want more information?

If you have any questions about this project, at any time, you can contact:

Isedora Lewis on Facebook Messenger or on izzynz@gmail.com

Or alternatively contact thesis supervisors at:

Maria Ulloa Maria.Ulloa@weltec.ac.nz

Wendy Scott Wendy.Scott@whitireia.ac.nz

Glossary of Maori Terms

Maori	English
<i>Whānau</i>	<i>Family</i>
<i>Takenga</i>	<i>Origin</i>
<i>Kaiuru</i>	<i>Participant</i>
<i>Ngā tikanga</i>	<i>Ethics</i>
<i>Tau</i>	<i>Age</i>
<i>Ira tangata</i>	<i>Gender</i>
<i>Kura</i>	<i>School</i>
<i>Nga korero</i>	<i>Stories</i>
<i>Kaiako</i>	<i>Teachers</i>
<i>Kaitiaki</i>	<i>Caretaker</i>
<i>Whakaaro</i>	<i>Ideas</i>

Appendix 5: Questionnaire



Research Questionnaire

Your participation in this study is entirely voluntary. If you choose to take part you are free to withdraw from the project at any time, and can withdraw the information provided, without any consequence.

Please check the box to confirm that you have read the Information Sheet about this research project and understand what it is about.....

Selective Mutism (SM) is defined as a consistent failure to speak in specific social situations, in which children are required to speak, despite speaking in other situations. SM is associated with significant impairment that last more than a month and is not affected because of language barriers or any other developmental disorder (Chavira, ShiponBlum, Hitchcock et al., 2007).

Little is known about the natural cause of SM, and most studies suggest that even though mutism may frequently remit over time, rate of talking behaviour remain lower than average, some residual psycho pathology such as social phobia and other anxiety disorders often persist (Chavira, ShiponBlum, Hitchcock et al., 2007).

Glossary of Maori Terms

Maori	English
<i>Whānau</i>	<i>Family</i>
<i>Takenga</i>	<i>Origin</i>
<i>Kaiuru</i>	<i>Participant</i>
<i>Ngā tikanga</i>	<i>Ethics</i>
<i>Tau</i>	<i>Age</i>
<i>Kura</i>	<i>School</i>
<i>Nga korero</i>	<i>Stories</i>
<i>Kaiako</i>	<i>Teachers</i>
<i>Kaitiaki</i>	<i>Caretaker</i>
<i>Whakaaro</i>	<i>Ideas</i>
<i>Tautoko</i>	<i>Support</i>

Questionnaire Instructions

- Please take your time to carefully consider your nga korero (stories) and answers.
- Feel free to write as much as you want and in as much detail as you would like.

- There is no word count, so feel free to write as many words as you feel is needed.
- Carefully consider each context, situation, the affects, beliefs and meanings of the nga korero you choose to tell.

Basic Demographic

Please circle the answer most related to you.

1. What is your current tau (age) range?

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2. What is your ira tangata (gender)?

Male	Female	Gender Diverse
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3. Please indicate whether you are doing any of the following?

Student	Full Time Employment	
Stay at home parent	Currently not working	
Part Time Employment	Other (Please state):	

4. In which country and city were you born?

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5. Where are you currently living?

6. Please introduce how you found out about your own Selective Mutism?

7. Please take the time to think and write down your experiences of being at kura (school) as a person living with Selective Mutism (SM), even if at the time you did not know what SM was.

- Include nga korero (stories) about how kaiaki (teachers) seemed to manage you in class and with your class mates.
- What was it like with your class mates and what was it like to make friends at this time of your life?
- Tell stories that include the kaiako , staff and other katiaki (support) services that did were involved in your story while at kura and whether these elements were of support.

A large empty rectangular box with a thin black border, intended for the respondent to write their answers to the questions listed above.

8. While you were at Kura (school), whether you were diagnosed SM, or maybe you did not know you were SM, how did some of the simple things asked from others, such as staff and students and yourself affect you?

- Talk about how you learnt to get by day to day.
- Talk about how your whānau (family) may have reacted to the nga korero (stories) your Kaiako (teachers) or other staff told about you at school.
- Talk about whether you have support from anyone, staff or students that made the day to day easier.

A large empty rectangular box with a thin black border, intended for the respondent to write their answer to question 8.

9. Looking back as an adult or young adult, what do you think could have been done or changed that could have meant a different experience while at kura (school) for you?

A large, empty rectangular box with a thin black border, intended for the respondent to write their answer to question 9. The box occupies most of the page below the question text.

Thank you for your time and thoughts in contributing to this research and contributing to the stories of Selective Mutism that could add benefit to others. If you would like to see the collated data and findings once complete please email me on izzynz@gmail.com.

Appendix 6: Proposal Approval Letter



26 October 2017

Isedora Lewis
c/o School of Social Services
Whitireia Porirua Campus

Dear Isedora

The Postgraduate Board of Studies met on 05 October 2017 to consider your application to proceed with your Research Proposal entitled '*The lived experience of Selectively Mute Adults in Education*'.

The Board has approved the research project **No: RP30-2017** for your Master of Professional Practice qualification. This research proposal has been assessed as of low ethical risk and you can now proceed as planned with your research project.

Please insert this letter as an appendix into your praxis/report.

The Board wishes you success with your research project.

Yours sincerely

A handwritten signature in black ink, appearing to read "E. Asbury".

Dr Elizabeth Asbury
Chair, Postgraduate Board of Studies

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