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# Finding A Voice: Exploring the Biographical Narratives of Adults with Selective Mutism

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A thesis submitted to the University of Huddersfield in fulfilment of  
the requirements for the degree of Master of Science by Research  
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## **Abstract**

This research explores the lived experiences of adults with selective mutism using interpretative phenomenological analysis. Existing literature has typically positioned selective mutism as a disorder of childhood and as a result little is known about the difficulties faced by individuals who continue to experience the effects of selective mutism throughout adolescence and adulthood. This research seeks to gain an understanding of the phenomenology of selective mutism as a lived experience and to allow participant's voices to be heard.

In-depth narrative interviews were conducted with six individuals who had continued to experience selective mutism throughout their adult life. Data from my own experience of suffering from SM were also included. Interpretative phenomenological analysis was used to identify five essential themes. These findings provide an insight into the embodied experience of selective mutism, the process of sense making in which individuals engage to negotiate their identities and the effects of social isolation. Furthermore this research explores the experiences of therapy and help seeking which were important topics within participant narratives.

This research encourages a thoughtful reflection on the lives of those whose realities have been profoundly affected by selective mutism. This research and the exploratory nature of phenomenological inquiry will hopefully encourage further investigations into selective mutism as it exists beyond childhood.

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# Chapter 1: Introduction

This chapter will detail my own interest in the phenomenon of selective mutism (SM) and outline my personal journey throughout this research. Issues regarding the present state of SM research and treatment will also be discussed, leading to an outline of the present thesis and the primary goals of this research.

## 1.1 Preface - My research journey

My own interest in the difficulty of selective mutism began from an ego-logical starting point; my own personal experience of the condition and the difficulties I faced whilst overcoming SM as an adult sufferer. Aspects of my own experiences as a sufferer of SM are documented throughout the analysis section, as I have chosen to include an auto-ethnographic component within this research. This study was also led by my previous research with sufferers of SM. As part of my degree dissertation I conducted four asynchronous online interviews with sufferers of SM. I was struck by how demoralised these individuals felt: where therapy had failed or provided little help the result was that individuals were left without hope, resigning themselves to a bleak and silent existence. Their concerns drifted towards the existential, towards isolation and meaninglessness, and for some, towards death.

What could be done in the future? What was being done for adults with SM currently? On these topics scant research existed and none which concerned adult sufferers. Widely cited as a childhood disorder there are only sporadic mentions of adults within the literature. This elicited further questions, such as how SM might progress as children became adults, how might it affect the lives of adults differently from children and what happened when these individuals seek help for a difficulty that is rarely recognised in adults.

For these questions to find meaningful answers an effort would be required which would sufficiently represent the voices of those who had thus far remained unheard. That is where this research began. Each decision made from that starting point has been chosen to facilitate an understanding of the lived experiences of



adult sufferers and to represent these findings in a way which gives such individuals a presence within the literature.

This endeavour has led me towards a greater phenomenological-existential understanding of suffering, providing a much broader theory which now underlies my epistemological position. Throughout my research journey, and from engaging with individuals whose lives have been drastically altered by SM, I have gained a greater appreciation for the intricacies of the life-worlds of sufferers and the importance of their unique lived experiences. Increasingly however I have become disillusioned by the often overly simplistic, unrepresentative and on occasion uncompassionate inclinations of the mainstream psychological literature concerning SM.

When an individual speaks of such experiences as crippling loneliness, thoughts of death and escape, and perhaps ultimately a journey towards overcoming SM, it is an often moving and always enlightening opportunity to understand SM from a new perspective. I have found it increasingly disagreeable to reduce this to mere psychology; to divide such experiences into inner values and external facts, to decontextualise it, to frame it as if it were something quantifiable, measurable and mechanical. I have endeavoured throughout this research to document these accounts in an attentive and receptive manner which might do justice to the rich and complex human stories, and the voices of sufferers themselves, which may answer many of the questions this study seeks to explore.

One final preface to this thesis concerns the use of the word suffering. Throughout this research I refer to individuals who suffer from SM. I am aware that some individuals may object to this, preferring instead more neutral expressions. I believe that to do this however would fail to truly capture the experience of living with selective mutism. From my own personal experience and as will be seen from the data provided by participants, the experience of having SM is the experience of suffering, hence the use of the term within this research.

## **1.2 Selective mutism & the aims of this research**

Selective mutism (SM) is an uncommon difficulty whereby sufferers find themselves unable to speak in certain social situations. This often results in sufferers experiencing a diminished social world and comorbid difficulties such as anxiety and depression. Few studies have attempted to explore the experiences of adult sufferers, and none have yet done so in depth. A convoluted history of contradictory diagnostic descriptions, a complex dynamic of co-morbid difficulties and the silence which characterises SM have each contributed to the dearth of knowledge regarding the experiences of sufferers themselves.

This study will provide a phenomenological exploration of the lived experiences of sufferers of selective mutism, including accounts in which they have sought, engaged with and progressed through therapy. Existing psychological research concerning effective therapeutic technologies has taken a therapist-centric perspective, employing varied arrays of psychometric and statistical measures to evidence effective therapy, with minimal consideration for the client's own perspective. This issue is further complicated due to the inherent communication difficulties faced by sufferers. Thus it can be a difficult and time consuming process to uncover the client's feelings, thoughts and experiences. The result has been that the majority of studies forgo this endeavour entirely, relying almost exclusively on observer ratings of therapeutic outcomes.

Studies which have employed qualitative methods to explore the experiences of clients engaging with therapy for various other psychological difficulties have documented a number of consistent themes. These studies have suggested that non-specific therapeutic factors are significantly more relevant to therapeutic change than therapy specific factors (Lambert, 1992; Norcross & Lambert, 2011) as are factors which lead to increased autonomy and self-reflection (Yalom, 2002; Messari & Hallam, 2003). A number of similar studies have found that patients often feel that longer term therapies would have been more beneficial (Yalom, 2002; Western & Morrison, 2001) in contrast to the typically short-term cognitive and behavioural therapies commonly available within the UK and which are typically provided by the NHS. Such explorations into client experiences have also shed light on client reflexivity, the manner by which clients are actively

aware of their engagement with therapy, pursuing agendas which may not always be apparent to the therapist (Rennie, 1994, 2001). This may range from attempting to appease the demands of the therapist, attempts at avoiding conflict or covertly manoeuvring therapy in a direction the client feels will be most productive. Such topics demand increased explorations of the contextual and relational dynamics of therapy if they are to be properly understood. Feltham (2005) has argued that the relational and contextual spheres from which sufferers construct meanings and understandings surrounding their difficulties are inherently inconsistent with cognitive and behavioural models of treatment, which are commonly used to help sufferers of SM. For those approaches such factors, if they are considered at all, are viewed as unfortunate confounding variables, with little role in the efficacy of therapeutic technologies. How such issues may directly affect sufferers of SM as they engage with therapy in the face of their inherent communication difficulties remains to be understood.

From the sparse literature a majority of studies have focused upon issues of classification, resulting in several varied and often contradictory conceptualisations of SM. A second issue stemming from the fact that, until the DSM V selective mutism was categorized as a disorder of childhood and infancy, is that it is unknown to what degree existing findings are relevant to the experiences of adult sufferers. This has led to a paucity of research to which health care professionals are able to turn to when attempting to help adolescent and adult sufferers, as almost all treatments documented within the literature have utilised services and technologies which were specifically appropriate for children (Calhoun & Koenig, 1973; Dow, et al., 1995; Moldan, 2005).

Qualitative explorations of client-centric experiences of therapy have previously led to valuable insights into the specific therapeutic factors which are valued by clients and which may influence future treatment strategies (Messari & Hallam, 2003; Bates, 2005). This is important for furthering our understanding of SM as there is no current consensus regarding the precise nature of the difficulty or how best sufferers can be helped to recover. As well as the potential practical benefits of this study it is also important to consider the personal impact a phenomenological perspective can provide. As both Gadamer (1975) and Van Manen (1990) have argued it is important not to simply ask what can be done with

phenomenological knowledge but to consider what a phenomenological understanding of experience can do with us. Such knowledge may challenge the existing assumptions of both therapists and researchers and thus decentralise current therapist-centric perspectives in favour of a co-constructed understanding of what it means to engage with and experience therapy for sufferers of SM.

To summarise, the goals of this study are:

- 1) To explore and elucidate the journeys of adults with SM who have engaged with healthcare services, including general practitioners, counsellors and therapists.
- 2) To explore how individuals with SM make sense of their difficulty and what SM and the journey of recovery from it has meant to those individuals.
- 3) To consider the implications that sufferer experiences of therapy may have for mental health professionals and the future development of effective interventions for adult sufferers of SM.

### **1.3 The structure of this thesis**

Chapter 2 of this thesis details the literature concerning SM. This begins with a summary of the history of SM research and how this has influenced contemporary conceptualisations which link SM to anxiety disorders. The chapter details the epidemiology and aetiology of SM and critically assesses studies which have thus far attempted to explore the experiences of sufferers and define selective mutism. The second half of the literature review explores research concerning the treatment of SM, including both practical interventions and the theoretical underpinnings of cognitive, behavioural and pharmacological interventions. Throughout this chapter the current gaps in knowledge will be highlighted and the section will conclude by summarising the issues which may be addressed by taking a phenomenological approach to explore the experiences of sufferers themselves.

Chapter 3 details the philosophy and framework of interpretative phenomenological analysis (IPA) upon which this research is based. This methodology is employed by the present study as a means of exploring a client-

centred perspective and the lived worlds of sufferers of SM. This chapter will also detail how my own experiential knowledge of SM has informed and been incorporated within the present study. A number of critical issues regarding IPA and insider research will also be considered. The chapter will conclude by outlining the research design, methods of analysis and ethical considerations important to this study.

Within chapter 4 the themes identified throughout participant narratives are presented alongside a discussion engaging with relevant psychological and sociological literature. The first theme explores the nature of SM as it is experienced by participants, including the embodied experience of being unable to speak, the progression of SM and the way in which the silence of SM is felt to deny any hope of escape from silence. The second master theme explores the effects of isolation and how this experience was felt by participants to reinforce their silence by denying them the opportunity to overcome SM and leading to a felt separateness from the world and others. The third master theme, journeys towards recovery, explores participant decisions to seek help. The role of diagnosis within participant narratives is also explored as a turning point which provided individuals with a sense of hope alongside the assurance that they were not alone in their suffering, and that recovery was possible. The fourth master theme explores the accounts of participants as they described their experience of receiving support from counsellors and therapists and the detrimental role played by SM in disallowing productive therapeutic relationships to develop. Participant views on CBT therapy, which all six participants had received, are also explored and a number of difficulties and challenges which participants faced in regards to this are highlighted. The final theme explores participant orientations towards the future, mirroring the close of each participant's narrative interview and providing a further insight into their current experience of SM.

The final chapter of this thesis summarises the main findings of this research, possible paths for future research and the potential impact of these findings for our understanding of SM.

# Chapter 2: Literature Review

This chapter will evaluate the existing research concerning SM, identifying the key areas of dispute and a number of gaps in our present understanding of SM. This will lead to a discussion of currently available therapies and the systems of care available in helping sufferers to overcome SM.

## 2.1 Aetiology, epidemiology and classification

This section will introduce SM as it has been documented and studied within the literature, outlining how our understanding of this difficulty has evolved over time. Each of the major theories which have attempted to explain the difficulty will be covered and critically discussed. This section will also explore some of the limitations of the exiting research which has led to the varied aetiological theories concerning SM. This will allow the present study to be viewed in context with previous literature as well as providing a comprehensive overview of the background literature which has informed our understanding of SM.

### 2.1.1 History & Diagnostic criteria

Our understanding of SM has transformed considerably since the difficulty was first identified by Kussmaul in 1877. Initially referred to as 'aphasia voluntaria' and later 'elective mutism' (Tramer, 1934) the difficulty was believe to be a manifestation of childhood oppositional defiant disorder (Reed, 1963; Wergland, 1979). Research from this period describes the nature of the behaviour as passive aggressive, assuming that, as the child was clearly able to speak in some situations, they were choosing to withhold speech in others. Despite a drastic shift in our understanding of SM from these early conceptualisation and the fact that these assumptions relied exclusively on the interpretations made by observers (parents, teachers, therapists, etc.) there remain examples of contemporary research which position SM as a refusal to speak (Remschmidt, et al., 2001; Omdal, 2007; Scott & Biedel, 2011).

Several early theorists suggested that SM was due to severe childhood trauma. Kolvin and Fundudis (1981) suggested that SM should be divided into elective

mutism and traumatic mutism, trauma being evidenced by co-morbid enuresis and soiling in the 24 selectively mute children which Kolvin and Fundudis studied. Almost all support for theories suggesting trauma arose from interpretations made by either parents or researchers rather than the sufferers themselves. Such theories may be viewed as product of a paradigm within psychology which positioned emotional trauma as the main causal factor in numerous psychological difficulties rather than evidence of a common etiological factor of SM. Such historical theories have been largely overtaken within contemporary literature in favour of anxiety based etiological models which are central to the present cognitive behavioural paradigm within psychology (Beidel & Turner, 2005; Bergman 2013). However researchers must be wary of disregarding such factors outright or replacing one overarching causal hypothesis with another while ignoring the unique experiences of individual sufferers. For example, Anyfantakis, et al., (2009) documented a case study of a four year old girl who developed SM after being attacked by a dog, noting that the child refused to participate in most conversations, relying on non-verbal methods instead, for a six month period. Though cases such as this are rare they suggest that selective mutism may indeed arise from traumatic experiences in some instances. Despite attempts to reconcile data with theory, by attempting to distinguish various sub-types of SM as Kolvin and Fundudis did or by positioning selective mutism as a symptom of childhood PTSD (Anyfantakis, et al., 2009), these efforts have highlighted the problems inherent in attempting to define psychological difficulties based on the interpretation of observable symptoms. This issue has been consistent over the past century regarding research into SM.

A further challenging issue surrounds the disparate diagnostic criteria used by researchers, which are most commonly taken from the DSM (See Table 1). Prior to 1994 diagnoses were based upon interpretations of the child's refusal to communicate, which may have been limited to a single situation, and which was usually linked to developmental disorders. From 1994 onwards the difficulty was instead described as a failure to speak rather than a refusal. Gradually communication and developmental disorders were dropped as associated features, being replaced with an emphasis on co-morbid anxiety disorders.

Table 1. Significant alterations between each iteration of the DSM for the diagnosis of Selective Mutism.

	Diagnostic Features	Associated Features	Course
DSM III (1980)	Disorder of childhood. Refusal to speak in most situations, language development deficits, articulation abnormalities	Shyness, enuresis, encopresis, school refusal, behavioural and learning difficulties.	Onset during early childhood. Most cases last weeks/months.
DSM III-R (1987)	Disorder of childhood. Persistent refusal to speak in more than one social situation. <b>Not</b> a symptom of social phobia	Shyness, speech disorders, behavioural and learning difficulties.	Onset during early childhood. Most cases last weeks/months.
DSM IV (1994)	Disorder of childhood and adolescence. Failure to speak in some social situations. <b>Not</b> solely due to lack of language ability or knowledge. <b>Not caused</b> by a communication disorder.	Shyness, fear of social embarrassment, possible associated communication difficulties, social phobia, possible language skills deficit.	Onset during early childhood. Most cases last weeks/months. Some cases persist for several years.
DSM IV-TR (2000)	Disorder of childhood and adolescence. Failure to speak in some social situations. <b>Not</b> solely due to lack of language ability or knowledge. <b>Not caused</b> by a communication disorder.	Shyness, fear of social embarrassment, social phobia, normal language skills.	Onset during childhood or adolescence. Cases last longer than one month, may persist for several years, may become chronic.
DSM V (2013)	Anxiety disorder. Failure to speak in some social situations. <b>Not</b> due to lack of language ability <b>Not</b> associated with a communication disorder.	Shyness, fear of social embarrassment, normal language skills, co-morbid anxiety disorders.	Cases last longer than one month, may persist for several years, may become chronic.



The result is that there are several disparate forms of SM which have been identified historically and thus much of the literature may concern a form of SM which shares minimal similarities with the condition as it is presently understood. Conversely in some instances the diagnostic criteria employed may have created self-reinforcing tautologies which have not yet been challenged. For example early research identified SM most commonly in children under 5, this was reflected in the age of onset criteria in the DSM-III, following research employed this criteria and thus the most studied population of individuals became children under 5 years of age, cementing the notion that SM is a childhood disorder and resulting in virtually no acknowledgement of adult sufferers within the literature to date.

### 2.1.2 Epidemiology

SM is believed to be a rare condition with prevalence rates estimated to be between 6 to 8 cases per 1000 children (Cline & Baldwin, 2004), though it has been suggested that these may be considerable underestimates due to the difficulties surrounding identification (Schwartz, et al., 2006; Roe, 2011). Such estimates are based on the manifestation of the difficulty during early childhood and do not factor in adult sufferers. Studies which did not rely on the DSM criteria suggested increased estimates (Sharkey & McNicholas, 2008). Referral to health care services occurs primarily between the ages of 5 and 8 (Stienhausen & Juzi, 1996; Schwartz, et al., 2006). However while SM may be easily identified in school age children there is little direct evidence to suggest that this coincides with the actual onset of the difficulty, which has been difficult to determine. The condition is believed to be slightly more common in females, with an estimated ratio of 1.6:1 (Anstendig, 1998). Krynski (2003) has suggested that the dearth of data regarding adolescents and adults with SM may be caused by their reluctance to seek help, a task which would invariably require speech and which adults may choose to avoid due the distress that such endeavours would entail. No research could be found which has explored whether the onset of SM can occur during adulthood, but the possibility is not necessarily excluded by the majority of aetiological theories.

### 2.1.3 Aetiology

There is no current consensus regarding causation, however genetic factors (Hagerman, et al., 1999), post traumatic stress disorder (MacGregor, et al., 1994; Anyfantakis, 2009), separation anxiety (Anstendig, 1999; Lehman, 2002), family dysfunction (Chavira, et al., 2007) and social phobia (Black & Uhde, 1992) have each been proposed as causal in the development of SM. Individuals with SM often present with various co-morbid difficulties further complicating issues of identification and classification. Identified co-morbid disorders have included Asperger's syndrome and Autism spectrum disorders (Bankier, et al, 1999; Wolff, 1995), anxiety disorders (Christon, et al., 2012; Bergman, et al., 2013), schizoid personality disorder (Wolff, 1995), dissociative identity disorder (Jakobsen, 1995) and depression (Bergman, et al., 2002). The nature of diagnostic categorization however means it is unclear in many cases whether SM has developed concurrently with other psychological difficulties or if it is an additional symptom of them.

Theoretical perspectives have attempted to account for predisposing factors which have been suggested to include poor emotional regulation and heightened experiences of anxiety (Black & Uhde, 1995; Moldan, 2005). Several cognitive-behavioural studies have suggested ways in which SM becomes self reinforcing. In a clinical case study Christon, et al., (2012) describe an adolescent girl who reported that she felt she could not speak perfectly and so would avoid speaking entirely, in turn leading to an avoidance of social situations. This then led to a lack of opportunities in which to speak and may have reinforced her belief that she would be unable to speak perfectly, diminishing her confidence and creating a self perpetuating cycle of anxiety and silence. Such detailed descriptions which take into account the perspectives of sufferers themselves are rare within the literature. Those which have been evidenced suggest that predisposing and maintaining factors can be diverse, including co-morbid difficulties, family dynamics and social skills deficits (Bonovitz, 2003; Lang, et al., 2011; Mitchel, et al., 2013). Such factors demand further investigation if an understanding of SM is to be achieved which goes beyond a conceptually weak and superficial generalisation of individuals with SM as representing a homogeneous group.

Familial vulnerabilities have also been observed in several studies. According to Remschmidt et al., (2001) only 18 of 45 mothers of the selectively mute children in their study could be classed as 'psychologically healthy'. Difficulties experienced by the mothers ranged from frequent mood changes, irritability and lack of drive, to chronic depression, brain damage and personality disorders. Though 40% of the mothers who took part presented with no such difficulties, the difficulties which were identified were suggested to be important factors in the development of SM in children. However with no in-depth investigation into situational and individual factors, how or why these issues resulted in children experiencing SM remains unknown. Cline & Baldwin (2004) observed that 40% of families with selectively mute children experienced 'marital difficulties'. However when this is compared to statistics similarly reflective of 'marital difficulties', such as divorce rate, which in the UK was estimated to occur in 45% of marriages between 2004 to 2005 (Office for National Statistics, 2012) the significance of such observations, and their influence on the development of SM, appears questionable from correlational data alone. Such an oversimplification of dynamic family relationships may be considerably misleading, for instance one may similarly suggest that depressed mothers of SM children and "atmosphere's that are not conducive to the expression of feelings" (Rosenberg & Lindblad, 1978) are products of SM within the family, rather than causal in the development of childhood SM. The significance of such factors is unlikely to be extrapolated from researcher observations which may serve to obscure the true importance of the dynamic family system as it reacts to the presence of sufferers with SM. Attempting to trace the onset of SM through a linear path of causality may be a futile endeavour.

Theories which have explored the origins of SM have been largely grounded in a developmental perspective of psychopathology which presupposes that difficulties such as SM are deviations from 'normal' developmental trajectories (Moldan, 2005; Bergman, 2013). Thus the goal has been to discover how SM as a maladaptive behaviour develops. While studies have independently explored family environment, early childhood experiences, genetic factors and cognitive abilities, they have been predominantly descriptive (e.g. Cunningham, et al. 2004; Anyfantakis, et al., 2009; Alyanak, et al., 2013). The complex interactions

between intra-individual and extra-individual influences which can result in the deviation of trajectories which begin from similar starting points, and the convergence of trajectories which begin from varied starting points, which should be central to achieving a developmental understanding of SM are missing from the literature. Instead the literature has provided disparate descriptions of observed behaviours and environments and attempted to accommodate these within prevailing frameworks and paradigms of the time (e.g. contemporary cognitive-behaviourism and the role of anxiety, developmental perspectives and family functioning), rather than allowing the data itself to inform a comprehensive and holistic theory. Thus while existing data suggest certain predisposing aetiological factors, such as childhood trauma, pre-existing psychological difficulties or poor emotional regulation, they have for the most part failed to provide any meaningful understanding of how those multiple developmental trajectories interact to influence the emergence or reinforcement of mute behaviour beyond the interpretations and speculations of researchers and clinicians.

#### 2.1.4 The role of anxiety

Although SM has only recently been categorised as an anxiety disorder a link between SM and social anxiety has long been demonstrated, though the precise nature of this relationship remains undetermined. Several correlational studies have found that individuals with SM often present with high rates of co-morbid social anxiety. Dummit, et al., (1997) identified anxiety or avoidant disorders in all 50 participants within their study. Similarly Black and Uhde (1995) found that 48 of the 50 children they studied met the diagnostic criteria for social phobia or avoidant disorders. From such data it has been hypothesised that SM may represent a severe form of social phobia (Black & Uhde, 1995; Stienhausen & Juzi, 1996). It may be argued however that simply because the conditions are often co-morbidly present it does not necessarily follow that mutism is an extension or more severe manifestation of an anxiety related disorder. It is possible that the relationship may be the reverse and that SM leads to social anxiety, or the relationship may be bi-directional.

Despite anxiety being put forth as a factor in the development of SM by several researchers (Garcia, et al., 2004; Beidel & Turner, 2005) a reliance on correlation

studies alone does not provide sufficient evidence to support such a hypothesis or elucidate this relationship to an informative degree. Over reliance on observer ratings of anxiety is a further confounding factor as it cannot be argued that observer ratings of anxiety and anxious behaviours necessarily confirm extant anxiety experienced by sufferers. Several studies have shown that where children have been asked to rate their levels of anxiety the results have not been significantly higher than for children with social phobia when measured using various psychometric inventories (Manassis, et al., 2003; Yeganeh, et al., 2003). This contradicts theories which position SM as a form of extreme social phobia or due to exceptional levels anxiety.

Emotional regulation theory (ERT) has been applied to a number of anxiety disorders and some attempts to incorporate this into an understanding of SM has been made (Cisler, et al, 2010; Scott & Biedel, 2011). ERT proposes that variations in anxiety between individuals are dependent upon that individual's ability to regulate their emotional arousal. This leads to compensatory behaviours which attempt to reduce distress when poor regulation occurs. In the case of SM an individual may regulate their emotional reaction (anxiety) by employing non-speaking behaviours. Such a theory would explain why individuals with SM do not produce higher anxiety scores than individuals suffering from social anxiety on psychometric tests. However this does not provide an explanation as to why such regulatory behaviour is manifest as mutism, rather than simply avoidance, or how remaining silent in a situation may make that situation less anxiety provoking. Furthermore this theory is difficult to explicitly evidence through the use of psychometric, behavioural or physiological response measures. Despite ERT acknowledging that individual experiences cannot be easily measured there have thus far been few qualitative studies exploring sufferers' experiences of anxiety as it is co-morbid with SM. As emotional regulation theories stipulate that emotional regulation deficits are individually experienced and difficult to quantify then evidence for or against such a hypothesis may only come from in-depth qualitative insights into experiential accounts of SM.

Despite the paucity of knowledge regarding the role of anxiety in SM, a majority of CBT, behavioural and pharmacological interventions documented within the

literature have been versions of treatments designed to treat anxiety disorders (Black & Uhde, 1994; Reuther, et al., 2011; Bunnell & Beidel, 2013).

### 2.1.5 The experiences of sufferers

There have been few qualitative explorations of sufferer experiences within the literature and those that do exist are often contradictory and suffer various methodological flaws. Omdal and Galoway (2007) attempted to explore the experiences of three children suffering from SM, aged nine, eleven and thirteen. Under the impression that direct questioning would cause the children to refuse to communicate, the researchers employed Raven's controlled projection for children (RCPC). RCPC requires that children write short stories about fictional characters, including references to how these characters think and feel. Analysis proceeds under the assumption that these fictional characters mirror the real children's experiences and attitudes. The results evidenced little more than the children's talents for creative writing. The notion that sufferers are unwilling to communicate is contradicted by a number of studies. As long as the methods employed facilitate communication with sufferers in ways which avoid direct verbal interactions then sufferers are capable and often willing to share their experiences when given the opportunity to do so (Roe, 2011; Christon, et al., 2012; Bunnell & Beidel, 2013). By employing RCPC the voices of sufferers remain ignored and any analysis is inherently removed from their true experiences.

A further study by Omdal (2007) employed thematic analysis to explore the recollections of six adults aged between 31 and 60 who had suffered from SM as children. Though none of the participants had ever been diagnosed with or treated for SM Omdal argued that they retroactively met the DSM-IV criteria. Furthermore several participants were asked to recall events and experiences from between the ages of two and four. Research into declarative memory has found that constructing memories of experiences prior to the age of three is extremely difficult and prior to age six only vague and fragmentary memories can be reconstructed (Nelson, 1993). Despite these potential flaws Omdal (2007) argued that the data evidenced participant desires to remain silent during their childhood, further citing various traumatic events as causal in the onset of SM, despite

participants describing the process as gradual, being themselves unable to recall any specific incident or occasion in which SM became manifest. This may indicate that no single event can be described as causal in all cases, with the onset being gradual rather than instantaneous, as other research has suggested (Ford, et al., 1998; Anyfantakis, et al., 2009). Omdal's study presents a picture which reflects the conceptualisation of SM as a conscious effort to remain silent which again contradicts the findings of other studies (Manassis, et al., 2003; Roe, 2011).

Roe (2011) conducted a study with 30 participants between the ages of 10 and 18 years old suffering selective mutism. Employing both closed and open questions alongside Likert scale measures. Although this method may limit the spontaneity and range of potential avenues of discussion it highlighted several issues previously unconsidered within the literature. Many of the children reported feeling isolated and lonely, a high number reported feeling as if they were missing out on life and were frustrated by their situation. When asked what they would like to tell people about selective mutism the overwhelming response was that they deeply wished to communicate but felt unable to do so. This contradicts the notion that individuals with SM are refusing to speak and engaging in purposefully oppositional or defiant behaviours. For some of the children the difficulty may have been context sensitive, as 19 children could speak comfortably with friends at home, while this number dropped to 12 when outside or at school with friends. The majority of children did not alter who they spoke to depending on the environment, suggesting that for some the difficulty becomes manifest depending on who they are with rather than the environment they are in. As individuals with SM may be heterogeneous in this regard, and may vary further depending on the presence of co-morbid disorders such as social phobia, this presents issues for developing an understanding SM if it does not take into account such subtle yet potentially influential individual differences.

Research which has attempted to identify the contexts in which individuals are able to speak has often been limited, giving minimal consideration to exploring complex scenarios which may lead to a more thorough understanding of the difficulties face by sufferers. For example studies often provide participants with self report questionnaires enabling participants to indicate the scenarios in which they can speak, e.g. at home with parents, at school in class, at school with

friends, etc. The result is a simplistic understanding of the situations, from those predetermined by researchers, in which sufferers are able to speak and does not illustrate how the individual copes with more complex scenarios where social contexts may overlap. Research based upon the assumption that silence is a manifestation of defiant behaviour may also risk marginalising contextual antecedents and broader reinforcing factors, this may have contributed to the dearth of knowledge and understanding regarding the complicated relationship between SM and social context. If however SM is experienced as a failure to speak despite a desire to speak, as growing research is suggesting, then understanding the social relationships and contextual factors which both facilitate and prohibit speech may be of considerable importance for understanding SM.

There are a number of possible explanations as to why there exists such varied and contradictory findings within the literature. Firstly there are the previously discussed issue surrounding diagnosis, with varying diagnostic criteria leading to the identification of potentially diverse forms of SM. There is also the potential influence of researcher bias on the interpretations of sufferer experiences due to a reliance on observer interpretations of visible behaviours. What is clear is that the studies which have thus far explored sufferer experiences have been insufficient in elucidating an in depth understanding of the lived experiences of sufferers and that the findings which do exist pertain, almost exclusively, to child sufferers.

## **2.2 Therapies for selective mutism**

A range of therapies for the treatment of SM have been described within the literature. Approaches have ranged from behavioural (Cohan, et al., 2006; Fisak, et al., 2006; Bunnell & Beidel, 2013) and cognitive-behavioural therapies (Fung, et al., 2002; Reuther et al., 2011) to group therapy (Sharkey, et al., 2008) and psychoanalytic therapy (Wergeland, 1979; Bonovitz, 2003) among others (See table 2). Selective serotonin reuptake inhibitors (SSRIs) are also regularly prescribed as treatment for children with SM (Carlson, et al, 2008). Published data regarding the effectiveness of therapies have typically been limited to single case studies. Research regarding the treatment of SM has been criticised as being methodologically flawed (Viana, et al., 2009; Scott & Biedel, 2011) as studies



often fail to adequately identify diagnostic procedures or the specifics of assessment.

Longitudinal follow-up data is also rarely gathered, though therapy is generally believed to result in more favourable outcomes with younger sufferers (Remschmidt, et al., 2001) and little is known about the long term development of SM. Conducting large scale studies has also been problematic owing to the difficulties surrounding the identification of sufferers and the rarity of the difficulty. As a result of the limited amount and scope of existing research no significant treatment protocols have been developed for SM and it is not uncommon for sufferers to receive treatment for anxiety disorders in lieu of this (Cohan, et al., 2006; Reuther et al, 2011). Characteristically, documentation of patient voices, opinions, thoughts and feelings are almost non-existent, with treatment effectiveness typically being judged by therapists/researchers, parents and teachers or through the use of standardised quantitative measures of anxiety reduction (See Table 2).

In the following section the various approaches to treatment, therapy and support will be discussed along with a critical consideration of the theory underlying each approach. This will conclude with a discussion of the gaps within the existing literature and what may be done to remedy this, culminating in the rationale for this study.

### 2.2.1 Behavioural interventions for selective mutism

The potential efficacy of behavioural interventions has been demonstrated throughout several studies. Primarily these have employed systematic desensitisation (Rye & Ullman, 1999), contingency management (Masten, et al., 1996; Vecchio & Kearny, 2009) and shaping (Porjes, 1992; Watson & Kramer, 1992). Though typically used for the treatment of young children (under the ages of six) some success has been demonstrated in treating adolescents using behavioural techniques (Bunnell, et al., 2013).

**Table 1a.** SM treatment studies published from 2000-2014

Author (Year)	N	Age/Gender	Design	Approach	Duration	Outcome	Follow-up
Fung et al. (2002)	1	7 years, male	Case study	Cognitive Behavioural: psychoeducation, anxiety management, social skills training, modelling	14 weeks	Some speech by session 10, lower measures of anxiety and impairment.	None
Bonovitz (2003)	3	6 years, female 7 years, female 9 years, female	Case study	Psychodynamic: Parent & child sessions	Unreported	Use of non-verbal communication	None
Moldan (2005)	1	6 years, female	Case study	Mutimodal: Cognitive Behavioural, Psychodynamic, pharmacological treatment	Unreported	Increased vocalisation with therapist, minimal vocalisation in a group setting	At 5 months spontaneous speaking was observed in group therapy settings
Fisak et al. (2006)	1	10 years, male	Case study	Behavioural approach: Social effectiveness training	23 sessions	Limited progress, minimal verbal interaction in school setting reported by teachers	Follow up 'several months' later, parental reports indicated some improvements in the child's speaking behaviours
Sharkey et al. (2008)	5	Mean age of 6.1 four females one male	Case study	Cognitive Behavioural: psychoeducation, group therapy, anxiety management, exposure	8 weeks	Lowered measures of anxiety and higher ratings of confident speaking post therapy (Clinician ratings)	None
O'Reilly et al. (2008)	2	5 year, female 7 years, female	Case Study	Behavioural approach: Social problem solving intervention	17-19 sessions	Audible vocalisations in a classroom setting.	3 month follow up, children maintained the taught skills

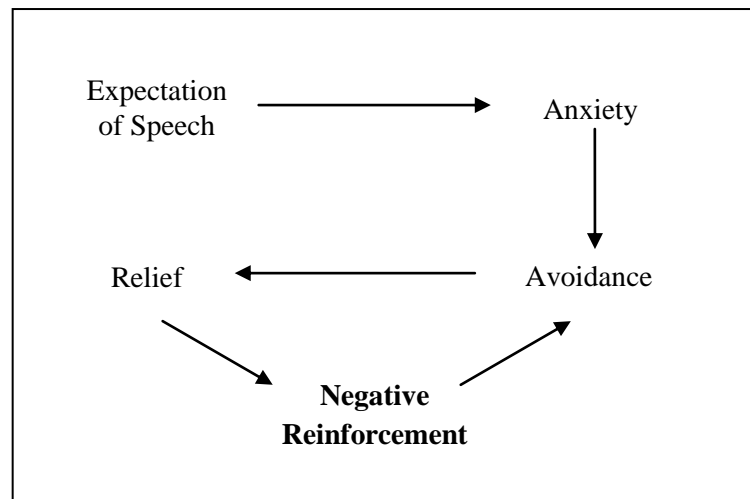
**Table 1b.** SM treatment studies published from 2000-2014

Author (Year)	N	Age/Gender	Design	Approach	Duration	Outcome	Follow-up
Oon (2010)	1	5 years, female	Case study	Multimodal: Behavioural intervention and drama therapy	18 sessions	Spontaneous speech with therapist, increased instances of speech reported at school.	One year follow-up, continued improvements at school, speaking behaviours observed with friends and teachers.
Lang et al. (2011)	2	9 years, female	Case study	Behavioural approach: role play and self modelling techniques	13 sessions	Increased incidents of speech when ordering from a restaurant during behavioural task	None
Reuther et al. (2011)	1	8 years, male	Case study	Cognitive Behavioural: Psychoeducation, exposure, cognitive restructuring, social skills development, pharmacological treatment	21 Sessions	Improvements on fear hierarchy ratings (Child & parent ratings) and improvements reported through clinical interviews	Improvements maintained at 1 & 6 month follow-ups
Christon et al. (2012)	4	15 years, female	Case study	Cognitive behavioural therapy: Psychoeducation, cognitive restructuring, parental training, exposure, social skills training	61 sessions	Parental reports indicated increased speaking behaviours, no longer met the DSM-IV criteria for SM	Continued to receive treatment for social phobia, communication with therapist and family is possible
Çöpür et al. (2012)	4	9 years, male 9 years, male 11 years, male 8 years, female	Case study	Pharmacological treatments: SSRIs - Escitalopram/Citalopram	4 - 7 months	Increased incidences of speech, unattributable to medication as factors such as therapy were not controlled for	None
Bergman et al. (2013)	21	Ages 4 to 8	Randomised controlled trial	Cognitive behavioural therapy, manualised sessions, using a waitlist control group	20 sessions	Parental/teacher reports of high levels of satisfaction. Significant differences between groups. Increased functional speaking	A 3 month follow-up reported significant differences from baseline for 8 of the 12 children who received CBT

**Table 1c.** SM treatment studies published from 2000-2014

Author (Year)	N	Age/Gender	Design	Approach	Duration	Outcome	Follow-up
Bunnel & Beidel (2013)	1	17 years, female	Case study	Behavioural approach: Intensive exposure, gradual exposure, desensitisation, social effectiveness training	18 Sessions	Intense exposure failed. Decreased anxiety ratings, increased reports of speech at school	1 week follow-up, depression inventory ratings unchanged, lowered anxiety ratings. Some qualitative improvements
Mitchel et al. (2013)	4	Mean age of 7 four female two male	Case study	Psychosocial behavioural approach: manualised treatment employing stimulus fading, shaping & contingency management	3 - 7 Sessions	Modest improvements on severity of behaviour measures & speaking goal attainment scores (Parent & teacher ratings)	None

One predominant behavioural model of SM developed by Bergman (2013) posits that the expectation of speech is the primary trigger of anxiety, the resultant behavioural response is then avoidance which provides relief from anxiety creating a cycle of negative reinforcement (see Figure 1.).



**Figure 1.** Bergman's behavioural model of Selective Mutism (2013)

The primary assumption of this model is difficult to verify, as evidence of anxiety has largely been drawn from observer ratings (Black & Uhde, 1995; Yeganeh, et al., 2003; Shriver, et al., 2011). Where children have been questioned about their own perceptions they have described themselves as possessing introverted qualities but not necessarily feelings of anxiety or nervousness. When self perceptions are compared to observer reports these discrepancies become evident. For instance in Roe's (2011) study while almost all observers perceived sufferers of SM as lacking confidence and being nervous and worried only three of twelve young people with SM reported correlating descriptions of their own experiences. This simplistic behavioural model also fails to acknowledge other potential reinforcing factors such as the role of increasingly diminished contexts in which the sufferer is able to interact with others, the impact of loneliness and depression, or the sense of futility and hopelessness which many sufferers experience (Hayden, 1980; Roe, 2011; Christon, et al., 2012), while furthermore assuming a homogeneity between sufferers regarding the role of anxiety.

A number of behavioural interventions have been documented as producing positive outcomes for sufferers, though this does not necessarily suggest that the

models on which they are based are accurate or that the manner in which the interventions are framed adequately describe the reality of what is occurring in therapy. While described in behaviourist terminology as exposure and desensitisation, such methodologies can also be seen as ways which enable an individual to learn and practice unused or undeveloped skills. Were treatment to be framed in this way it may be suggested that SM is caused in part by existing or felt social skills deficits. Some research has suggested that this may be the case (Fung, et al., 2002; Reuther et al., 2011) and a number of behavioural interventions have included social skills training components as an addition to behavioural therapy (Reuther, et al., 2011; Bunnell & Beidel, 2013). There is a considerable difference between reinforcing existing but diminished behaviours and helping an individual to develop new situation specific skills. Anxiety therefore may be an unhelpful label as it negates the authenticity of the individual's actual experiences, such as with theories of emotional regulation, which position a cognitive deficit within the individual. Furthermore by simply targeting anxiety through behavioural procedures, such as desensitisation and exposure, we may overlook anxiety as a reasoned response by individuals who are attempting to make sense of their experiences. If SM is, as Roe (2011) suggests, experienced as an uncontrollable silence despite sufferers wishing to speak then it may be unsurprising that this experience provokes anxiety. Anxiety therefore may be felt for numerous reasons, including the embodied experiences of sufferers, a real or perceived lack of social skills, or as a result of avoidance itself, which is unlikely to result only in relief and not, for example, in a sense of frustration or loneliness (Roe, 2011).

A behavioural case study by Bunnell & Beidel (2013), which uniquely within the literature documents an initially ineffective behavioural intervention, describes how Nina, a 17 year old girl with SM, responded to behavioural therapy. Bunnell & Beidel first devised a behavioural therapy which attempted to reduce anxiety, which as previously discussed in Bergman's (2013) behavioural conceptualisation of SM is believed to be felt in response to situations where speech may be expected. This intervention was based on an extinction paradigm and involved intensive exposure to 'densely populated locations'. Although a reduction in anxiety was found there was no effect on speaking behaviours, a result which may

contradict the theory that SM is sustained by or is an extreme form of anxiety. After reconceptualising treatment a new approach focusing on gradual desensitisation was developed. This began with an effort to elicit any vocal sounds, such as whispering, which eventually led to repeating single words, to answering questions and so on until speech began to occur naturally. While attempting a task which required Nina to speak at school it became evident that Nina was "deficient in numerous social skills" (Bunnell & Beidel, 2013, p. 301) resulting in a component of formal social skills training being provided. This suggests that adolescents and adults with SM may be aware of their own limited social skills and it reasonably follows that they may then attempt to avoid situations which could cause embarrassment or discomfort. Understanding this aspect of SM allows the sufferer to be positioned not as a passive victim of reinforced behaviours or disordered thoughts, but as a reasoning and reasonable agent attempting to reduce their own suffering. Framing SM in such a way may also enable us to better understand the often inconsistent speaking behaviours of individuals with SM across different contexts. It remains unclear however if social skills deficits result in SM or if prolonged silence itself is the primary cause of diminished social skills.

Case studies have document the difficulties which sufferers experience when transferring the skills developed, or reinforced, in one context and applying them to another (Lang, et al., 2011; Marc & Crundwell, 2011). Whereas anxiety models presuppose that anxiety is caused by across-context phenomena, such as the expectation of speech, the issues of transferability and the selective nature of selective mutism suggest a more influential role of social context. Sufferers of SM may thus be influenced not only by anxiety related to speech itself, but the context in which speaking takes place, those around them, the purposes of speech and numerous other factors.

It is uncommon for behavioural treatments within the literature to focus on eliciting speech in numerous contexts. This endeavour has been typically limited to the classroom environment (Fisak, et al., 2006; O'Reilly, et al., 2008; Oon, 2010). It may be important especially with adolescent and adult sufferers to recognise that speaking behaviours do not automatically become generalisable between contexts. A behavioural intervention which supports this was conducted

by Lang, et al., (2011) which attempted to reinforce speaking behaviours across multiple social situations. They reported that a general increase in speaking behaviour was minimal and that each situation had to be tackled independently. This again diverges from theories concerning social anxiety, where reductions in anxiety are expected to translate across contexts (Fung, et al., 2002; Reuther, et al., 2011; Bunnell & Beidel, 2013).

A further outcome study conducted by Bergman, et al., (2013) and one of the largest outcome studies to date, illustrates the difficulty in attempting to use third party ratings of recovery, where each party, in this instance teachers and parents, interact with children in different situations. Using behavioural interventions with twelve children over the course of twenty-four weeks, participants were assigned with a series of bespoke exposure exercises developed by both therapists and parents. Uniquely the study employed a waitlist control group comprising of nine children who did not receive therapy. Post treatment ratings suggested a slight increase in functional speaking behaviours within the treatment group, though the differences were not significantly different from the control. Some reduction in social anxiety was reported by the parents of the children, but not teachers. Bergman, et al., suggest that these results may have been due to the properties of the Social Anxiety Scale for Children-Teacher Version, which may not have been sensitive enough to evidence treatment effects. However conjectural opinions by third parties being employed to evidence a decrease in the emotional experiences of sufferers may be an inherently poor means of measuring their anxiety, assuming that the construct of anxiety is measurable. If recovery is experienced only in regards to specific social contexts and does not generalise to other contexts then such a method of rating participants recovery may be inherently misleading. Despite the recognition within behavioural practice of internal events, such as the experience of anxiety, such factors are not positioned as constituting meaningful lived experiences. As a result the means of documenting recovery which have been used by behavioural researchers, which have included documenting increased speaking behaviours within specific contexts and observational measures of anxiety, have failed to represent actual quality of life improvements for sufferers and may be both misleading and in some instances empirically unverifiable.



The only individuals who are able to report meaningfully on treatment success across all situations are sufferers themselves, though their voices are absent from the clinical literature. Observer ratings of behaviours, by teachers, parents or therapists should not necessarily be equated with actual recovery. The voices of sufferers, their experiences of behavioural interventions, and the complexity of contextual determinants on speech are all diminished by behavioural conceptualisations of SM. As a result of these issues and due to a lack of treatment comparison studies the true efficacy of behavioural interventions for SM remains unknown.

### 2.2.2 Cognitive behavioural therapies for selective mutism

Cognitive behavioural therapy is among the most commonly provided therapy in the UK for anxiety related difficulties (Lovel & Richards, 2000; Stiles, et al., 2006; Williams & Martinez, 2008). For the treatment of SM a modified CBT for generalised anxiety disorders has often been documented within the clinical literature (Fisak, et al., 2006; Reuther, et al., 2011). A number of studies have suggested that CBT may be effective in some instances, though these have been limited to single (Moldan, 2005; Oon, 2010; Lang, et al., 2011) or small group case studies (Bonovitz, 2003; Çöpür, et al., 2012). Thus far there have been no identified randomised control trials of CBT for the treatment of SM. As a result the existing clinical literature regarding the efficacy of CBT has failed to meet the criteria of the evidenced based ethos upon which support for CBT rests. Such studies, providing only superficial descriptions of potential causal factors also fail to generate any new insights into SM, as these studies have attempted to accommodate experiential or contextual factors into the pre-existing theoretical framework of CBT. It has been argued that CBT is overly focused upon practical outcomes of treatment (Pilgrim, 2008) and as a result it may be seen primarily as a treatment method which disconnects suffering from its social and contextual origins, focusing instead upon the 'disordered' thinking of the individual. Theories which have informed the use of CBT for SM have been cursory, primarily targeting the component of anxiety and the associated thoughts and beliefs suspected to sustain SM.

The observation that children who develop SM share similar temperamental and environmental characteristics to children who experience social phobia has led some to conclude that SM may itself be a symptom of social anxiety disorder (Kristenson, 2000; Cunningham, et al., 2004; Cleave, 2009). Thus assumptions have proceeded that CBT for anxiety disorders should also be effective for treating SM. However, similarly presenting difficulties do not in themselves evidence extant relationships between difficulties, nor can it be concluded that difficulties which appear similar can be treated in a universal manner.

This primary focus on anxiety extends to the evaluation of CBT as an effective treatment for SM. Clinical studies which have argued for the efficacy of CBT for SM typically utilise manualised treatments and measure patient outcomes through the use of quantitative measurements of anxiety reduction (Dummit, et al., 1997; Fisak, et al., 2006). One exception to this was a case study by Christon, et al, (2012) which employed modular CBT to treat a 15 year old female with SM. While treatment efficacy was partially measured via fear hierarchy ratings and depression ratings, with researchers employing the Revised Children's Anxiety and Depression Scale parent and child versions the study also employed the Selective Mutism Questionnaire (SMQ) to measure speaking behaviours over the course of therapy (Bergman, et al., 2008). While these results showed an improvement across the 61 CBT sessions for anxiety and depression the results of the SMQ were less conclusive. As this measure was primarily developed for young children it included items such as 'Speaks to Babysitter' and thus was likely inappropriate for measuring the speaking behaviours of a 15 year old. Despite the efficacy of CBT for SM being demonstrated by a reduction in anxiety several studies have reported that sufferers of SM can present without co-morbid anxiety related difficulties (Kopp & Gillberg, 1995; Kristensen, 2000), though this has received minimal attention within the literature. A dearth of studies which document follow-up sessions (See Table 2.) further limit the degree to which CBT for SM can be said to achieve long term effectiveness.

As Pilgrim (2008) has argued, CBT based research often fails to provide a voice for misery or human suffering. CBT automatically positions the difficulties which it attempts to treat as being the result of deviations from normal cognitive

functioning and 'correct' ways of thinking. The causes of psychological suffering are implicitly situated by CBT within sufferers themselves. In the case of SM this has been suggested to be due to the previously discussed theory that SM is a severe manifestation of social anxiety (Black & Uhde, 1995; Stienhausen & Juzi, 1996). Such theories presented within the literature however fail consider individuals suffering from SM as being situated within unique systems, with unique histories and life-worlds and with unique perceptions of their future trajectories. Such considerations would undermine CBT, running counter to the homogeneity required of what is contemporaneously considered evidence based practice. The 'gold standard' of empirically supported manualised CBT within the clinical literature highlights this deficiency. A universal manualisable therapeutic technology, which may be demonstrated through randomised controlled trials, demands a homogenously defined psychological disorder, uncomplicated by contextual, sociological or biographical factors unique to the individual. Such conceptually narrow models of treatment are evocative of the traditional medical model of illness, mirroring also the drastic power difference between an expert physician delivering a treatment technology and a passive patient, lacking all expertise. Such critiques have been discussed at length by a number of writers (Feltham, 2005; Pope & Vasquez, 2007), for the purposes of this study however it is important to acknowledge that the 'illness' is experienced only by the sufferer, and by others only to the degree that the sufferer is able to disclose. Studies which discount the world of the individual distance themselves from reality. The result, when such knowledge leads to the development of technologies used as universal treatments, is that it is not uncommon for patients exposed to CBT to feel misunderstood and as if they are not being listened to (Messari & Hallam, 2003; Feltham, 2005). Both are issues which are later discussed by several participants within the present study concerning their experiences of CBT. As a number of therapists have argued, the act of standardisation renders therapy less real and less effective (Yalom, 2002; Pilgrim 2008) and this may not go unnoticed by service users.

One potential evolution of CBT and of the current evidence based paradigm is to standardise therapy through the removal of the therapist, who themselves inhabit a unique life-world, and who have variable skills at providing and delivering therapy. Several treatments have been explored which eschew the therapist by

utilising online CBT delivery methods for treating SM (Fung, et al., 2002; Ooi, et al., 2012). Though no comparison between traditional clinic based CBT and online CBT delivery exists for SM a study by Kiropoulos et al., (2008) for sufferers of panic disorders, found that both interventions produced significant effects when measured using self report and clinician severity ratings. To employ a therapy which includes minimal one-to-one interaction with a therapist may be highly deleterious to recovery, and the potential to miss important factors such as diminished social skills, complex social factors, trauma and other issues which may affect recovery is increased. Furthermore while it may be important to explore new avenues of communication with sufferers of SM, including online means, the impact of omitting the therapeutic relationship, removing the genuineness and spontaneity of the therapeutic endeavour and other non-specific therapeutic factors may not be in the best interest of patients<sup>1</sup>. That these aspects are absent from internet based treatment programs, and yet that those programs in turn do not perform worse than traditional CBT (Spence, et al., 2011), should be of great concern to both patients and mental health practitioners.

Despite CBT being commonly presented as an empirically supported treatment this may not be true in the case of CBT for SM. No randomised controlled trials of CBT were identified within the clinical literature and case studies which have been conducted rely on measures of anxiety reduction, often based on inferences made by parents or researchers to evidence effectiveness. Once again, the experiences of sufferers themselves are marginalised or entirely absent from the clinical literature.

### 2.2.3 Miscellaneous interventions for selective mutism

Selective serotonin reuptake inhibitors (SSRIs) are often prescribed as a second line of treatment for sufferers of SM as an attempt to alleviate co-morbid difficulties such as anxiety and depression (Carlson, et al., 2008; Viana, et al., 2009). Black and Uhde (1992) conducted a controlled double blind study of the effects of the SSRI fluoxetine on children suffering from SM. Parental ratings

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<sup>1</sup> A number of issues surrounding the patient-therapist dyad and the importance of authenticity were discussed by the participants within the present research, discussed later in section 4.4.

from their study suggested a significant improvement, though ratings by clinicians and teachers in other contexts did not. Beyond issues concerning the use of observer measures a further explanation of these situational differences may be that SSRIs do not themselves influence mood, but act to enhance neural plasticity and neurogenesis, in turn increasing the degree to which environmental factors and the subjective cognitive appraisal of them are able to impact mood and emotion (Branchi, 2011; Harmer & Cowen, 2013). Any changes induced by SSRIs may have been context dependant thus the effect of SSRIs on behaviours at home may have been different from those at school or in a therapy setting. The majority of SSRI drug trials generally do not explore contextual influences on drug efficacy assuming an overall effect on cognition rather than inconsistencies across multiple social contexts.

A number of other approaches within the clinical literature have been documented including family and psychodynamic therapies. Family therapy conceptualises the behaviour of the selectively mute child as serving specific functions within the family dynamic. The goal of therapy is often to identify, recognise and eventually reconfigure the dynamic systems which bring about the mute behaviour (Meyers, 1984; Chivara, et al., 2007). Alyanak et al., (2013), conceptualising SM as a refusal to speak, argued that mute behaviour may arise from an imbalance of power within the family system and the child's desire to attain control and relief. The researchers suggest that was caused by the behaviours of an over-controlling mother and a lack of emotional closeness within the relationship. While these issues may have been extant within this family dynamic the relevance of such a family system and the wider development of SM is unclear. In the majority of cases described individuals with SM are able to communicate without difficulty with close family, most often with parents and siblings (Cline & Baldwin, 2004; Roe 2011). Employing a family-systems perspective in this way presupposes that the behaviours being studied are reinforced or caused by the family dynamic itself, with the child's behaviour being viewed as a self-serving method of manipulation and control, rather than viewing the family dynamic as being altered by the existence of a child within that system who suffers from SM. Without such assumptions a lack of emotional closeness may be seen as a result of the child's mutism, rather than the cause of it. As a result family dynamics may be far more

ambiguous than research has assumed. Furthermore as speaking behaviours are typically preserved within the family unit the effectiveness of family therapies for treating SM may be limited.

A small number of psychodynamic interventions have also been used to treat SM in children. This perspective conceptualises SM as a product of delayed grief and, in contrast to theories underlying family therapies, to a manifestation of stranger anxiety (Lesser-Katz, 1988; Valner & Nemiroff, 1995). Psychodynamic interventions have taken the form of art and play therapies (Oon, 2010) and have typically been employed to treat children below the age of five. These therapies have found some success in eliciting speech. Though such studies often provide rich interpretations of the child's world these are filtered through the lens of the psychodynamic approach and thus may tell us more about the interpretations of researchers than about the lived experiences of children with SM.

## **2.3 Rationale**

While proponents of the treatments described may argue that factors such as the therapeutic relationship, client perspectives and considerations of wider contextual systems are not unimportant within therapy they are however absent from the clinical literature. Situated within the evidence-based paradigm it is necessary for such studies to present an image of a scientific endeavour free from the qualities of compassion, genuineness and spontaneity. They aim to present a standardised picture of therapy and this demands an equally homogenous presentation of the sufferers who engage with those therapies. The methods employed to evidence the success of such therapeutic interventions are similarly limited by the need to keep up scientific appearances; evidence from therapists, parents and self reports are presented as if they were non-subjective and thus the actual rich and subjective nature of experience which might facilitate our understanding of SM is lost. Outcome measures have ranged from ratings of anxiety to documentation of instances of whispering in the classroom, though it remains unclear if these measures evidence recovery from SM, from either a medical perspective or from the perspective of sufferers themselves.

The existing literature is limited in other ways; we know little about how sufferers seek therapy whilst experiencing SM, or how they themselves experience talking therapies when they may be unable to speak in those situations. In short anything which would demand a consideration of the perspectives of the individuals who have SM is missing from the existing literature. The result is a body of research that can present only basic, homogenous, static conceptualisations of what are unique and dynamic multifaceted realities. A number of alternatives and challenges to the therapist-centric and therapy-centric ethos within psychology have been put forth, including the need for increased qualitative research and the need to distinguish between evidence-informed psychology and evidence-dominated practices (Mahrer, 1985; McLeod, 1999; Fletham, 2005)

To address these issues the present study will employ an interpretative phenomenological stance and aims to address a number of the issues and gaps highlighted throughout this literature review. This study will explore the narrative accounts and experiences of healthcare service users who suffer from SM as they have sought and engaged with various therapies and treatments. In doing so this study will explore what it means to be selectively mute, to seek help and engage with the help provided from the clients own perspective. The study will explore the power relations in therapy as they are experienced by sufferers of SM, what recovery means to the sufferer and may shed further light on the role of anxiety within SM. Importantly, this study will give a voice to individuals whose voices have thus far been silent within the literature. To restate, the aims which have emerged and which will be explored in the present study are:

- 1) To explore and elucidate the journeys of adults with SM who have engaged with healthcare services, including general practitioners, counsellors and therapists.
- 2) To explore how individuals with SM make sense of their difficulty and what SM and the journey of recovery from it has meant to those individuals.
- 3) To consider the implications that sufferer experiences of therapy may have for mental health professionals and the future development of effective interventions for adult suffers of SM.

# Chapter 3: Methodology

This chapter will detail the philosophical influences which underpinned the present phenomenological inquiry and discuss the reasons for this selected methodology. The appropriateness of the chosen methodology will be considered in regards to my own status as an insider researcher and the manner in which this identity has been incorporated within this research. Finally this chapter will document the interview design and the processes of analysis.

## 3.1 Philosophical Influences

The aim of the present study was to gain an in-depth understanding of the lived experiences of adults suffering from SM, with a further focus on the experience of seeking and receiving treatment. It was imperative that the methodology selected would facilitate an understanding of lived experiences and would be receptive to the voices of participants, positioning their data at the forefront of the research. The initial research question asked 'what is the experience of being selectively mute like' and was itself phenomenologically oriented, placing value upon the experiential nature of suffering from SM. This question positions individuals as active respondents to the external world who are actively engaged with formulating meanings and interpretations around their experiences. Exploring life narratives may thus provide a meaningful insight into this aspect of SM. For these data to be useful and impactful the selected methodology also had to allow for a dialogue between the ideographic data collected and the overwhelmingly nomothetic orientation of the existing literature. It was for these reasons that interpretative phenomenological analysis (Reid, et al., 2005; Smith & Osborn, 2008) was chosen as the method for this research. IPA places significant emphasis on capturing the richness of participants' experiences while also enabling the analysis to engage with relevant theory, where appropriate, alongside the inductive analytic process itself.

Beyond IPA however a number of other phenomenological orientations influenced the present study. Though there are a number of phenomenological constants and areas of overlap which exist between the main theoretical



approaches to phenomenological inquiry, one aspect which divides these various schools and which was especially pertinent to the present study, surrounds the concept of phenomenological reduction. This refers to the bracketing of pre-understandings, which Husserl described as the epoché (Husserl, 1982), which constitutes the putting aside of preconceptions and existing knowledge. This however seemed incompatible with the essence of lived experience, presuming that it would be possible to a large degree to step outside of the sphere of our experienced realities into something closely approaching an unbiased, objectivist position. As I have personal experience of suffering from SM my own identity, interpretations, knowledge and my trajectory through life have been inexorably influenced by the difficulty which is at the heart of this study. I can no more set aside these aspects of my existing reality than I could set aside the colour of my eyes. I cannot set aside its facticity as it is not fact but an experienced reality.

A number of phenomenological schools however have contravened the notion of bracketing for such reasons, as Van Manen (1990, p. 47) argued, "If we simply try to forget or ignore what we already know, we might find that the presuppositions persistently creep back into our reflections". IPA research is divided on the use of bracketing, whilst some studies incorporate the Husserlian concept of bracketing alongside the double hermeneutic process of interpretation (e.g. Goldsworthy & Coyle, 2001) others eschew this aspect in favour of a critical self awareness as a response to the inevitability of researcher influence (e.g. Finlay & Gough, 2003; Lavery, 2003). Within this study it was decided that the concepts of reduction within Heideggerian phenomenology and the phenomenology of Van Manen were more appropriate, emphasising the importance of recognising pre-understanding and the hermeneutic process of interpretation. To facilitate the recognition of my own experiences I chose to include myself as a full participant within this research.

Beyond the strengths of IPA being grounded within the data (Smith & Osborn, 2008) and combining the ideographic, double hermeneutic and psychological components of analysis, one weakness is that IPA research has the potential to neglect consideration of the essential structures of the lived worlds of individuals. IPA research has also been criticized as constituting a mechanical analysis (Rodriguez, 2009) with an over-prescriptiveness of the analytic method which,

while this may sustain IPA as a rigorous methodological process, may also cause it to lose the spontaneity of other forms of phenomenological research. Employing a methodology criticised for being overly mechanical did not seem fitting for the present study. It was for these reasons that the methodology employed was also heavily influenced by the phenomenology of Van Manen (1990) and the approach of the Sheffield school of phenomenology developed by Ashworth (2003). These concerns were dealt with in several ways.

Though Van Manen's phenomenology similarly rests on the principles of thematically analysing data this process is afforded greater flexibility than IPA, though no less rigour, in recognising the important role of the analyst in constructing meaning from the data. While this is similar to the double hermeneutic process central to IPA a greater emphasis is placed on dwelling within the data and maintaining a strong orientation towards the phenomenon, investigating it as it is lived rather than as it may be conceptualised. I felt that these facets were important in relation to the goal of providing sufferers of SM with a voice: a goal which may have been potentially stifled by the prescriptive analytic method of IPA. Van Manen also proposed a number of core existential structures of the life-world including temporality, spatiality, corporeality and sociality. These existential structures are both mirrored and expanded upon by Ashworth (2003) with the addition of discourse, project (how an individual may perceive their ability to perform activities central to their lives), selfhood and embodiment. These existential givens of the life-world acted as a foundation for interpretation within this analysis providing a core structure which is lacking in IPA whilst still resting on no assumptions beyond the existential givens of lived experience.

In the present study the methodology of IPA lent a structure to the process of data collection and analysis, while the work of Van Manen and the Sheffield school of phenomenology were incorporated to further facilitate and expand upon the analytic process. These further influences served to address several critiques of IPA and strengthen the overall methodology by bolstering both the theoretical and practical components of this research. This was done in an effort to fulfil the goal of adequately exploring, representing and understanding the lived experiences and life-worlds of individuals suffering from SM.

### **3.2 An insider perspective**

During the course of this research my own status has shifted at various points, as rather than insider status being a fixed position I have found it to be a dynamic and fluid process of engagement. At times I felt that my own status as a prior sufferer of SM helped to engender a shared identity during interview sessions, facilitating the open and honest dialogue required in phenomenological research. However this would also give rise to a number of challenges in overcoming potential assumptions of sameness for both myself and for participants.

While the illusion of sameness within insider research has been discussed within the literature it has tended to focus on the researcher's position, rather than those of participants (Hurd & McIntyre, 1996; Pitman, 2002). However I found that participants were also liable to assume a shared understanding. As a result I often had to inquire further into the specifics of an individual's experiences, as there seemed to be a temptation among participants to assume that I already knew how SM was experienced. I found that the best approach was to be as open and honest with participants as possible in making certain that they understood that I was not actively looking for shared experiences but valued also those areas where our experiences diverged and that their own experiences were valuable in themselves. Once this understanding had been established I found that participants were extremely willing to discuss their own experiences. I believe that establishing this collaborative alliance with participants was fundamental to this research and though it would have been possible without my insider status it is likely that this facilitated the process of generating a trusting, open and genuine dialogue with participants.

During this research I was aware that my status as researcher and my role in interpreting the experiences of participants placed me separately from the other participants within this study. This imbalanced situation could potentially have given (or been perceived to have given) my own voice significantly more power within this research. To address this I decided to alter several aspects of this study from traditional IPA research designs. Simply disclosing my own status felt insufficient, as Clifford & Marcus (1986) have suggested, disclosure alone may result in the researchers voice becoming a 'hidden, yet omniscient presence' within

the research, at the same time however I did not wish to overshadow the contributions made by the other participants. It was for these reasons that I decided to include myself as a full and equal participant within this research. This began with writing my own narrative account concerning my experiences of living with SM. Sections from this document have been incorporated where appropriate into the present study, presented alongside excerpts taken from participant transcripts. Incorporating my own voice has served to further answer the research questions posed by this study while also addressing possible power imbalances which may have arisen as a result of insider IPA research and self-disclosure.

One further decision to combat the potential illusion of sameness and to give participant voices a greater presence within this work was to consult participants during a third and final interview with the preliminary themes which had emerged from the analysis. This method follows the proposals of Heron (1996) regarding co-operative inquiry, emphasising that research should be done with rather than on people. Though participant input is not usually sought at this point within IPA research I felt that doing so would serve to ensure that the themes identified successfully represented the core experiential phenomena relevant to SM in the eyes of sufferers themselves. This also allowed participants to be more fully involved with the analytic process, providing participants with a further voice within this research and partially equalising the power differentials associated with my own status as an researcher.

### **3.3 Design**

This section will outline the design employed by the present study and the rationale behind each of these design choices. This will cover recruitment, the use of narrative interview methods, ethical issues and the analytic process. This section will conclude with a brief introduction to the seven participants who took part in this study to provide a greater context to their stories and to the themes which emerged from them.

### 3.3.1 Recruitment

The study used purposive sampling. Participants were recruited using online advertisements directed at forum communities for adult sufferers of SM. Participants were self selected, ensuring that those who chose to take part felt comfortable communicating online. It should be noted that as a result this sample may not represent the most severe cases of SM where even written communication may be avoided (Roe, 2011). Nevertheless this method of sampling allowed for a broad range of sufferer perspectives, including both current sufferers and those who considered themselves partially or fully recovered. As this study aimed to explore both converging and diverging emergent themes between participant experiences of SM and of therapy for SM it was decided that selection criteria would not be based upon the duration or type of therapy participants may have received. It was decided that only participants from within the UK would be asked to take part to ensure that practices such as diagnosis and treatment were concordant with UK standards. This also ensured that, should any participant have requested information or support, appropriate local or nationwide sources of assistance could have been recommended.

Only those who met the following criteria were excluded from taking part:

- Individuals under the age of 18 or who were unable to provide informed consent
- Individuals with SM who were unable to communicate through typed text or who did not have online access.
- Individuals living or receiving treatment outside the UK.

After initial contact with participants had been made further information regarding this study was emailed to participants. This included an outline of the interview schedule and provided an opportunity for participants to discuss any concerns prior to taking part. Consent forms were e-mailed once participants had received and responded to the initial information sheet.

### 3.3.2 Online narrative interviews

As the questions this study attempts to answer concern a broad range of life-experiences it was decided that a biographic-narrative interview method (e.g. Wengraf, 2001) would be most appropriate in capturing the full detail of participant's lived experiences. This method of interviewing allows for an exploration of experiences as they are recounted alongside their unique historical and social contexts to a greater degree than traditional unstructured or semi-structured interview techniques. Non-narrative interview methods often fail to take into account the chronological order and flow of life events, utilising narrative methods allows an insight into the present moment of recollection as well as into participant orientations towards both the past and future. Moving beyond the question-answer scheme of traditional interviews allowed for participants to give more coherent and potentially more valid accounts of their experiences as the interviews followed the self-generating schema imposed by the interviewee themselves. As Bauer (1996) has argued data gained during question-answer interviews may reveal more about the interviewer's own position than the relevant structures under investigation. Furthermore, as IPA stresses the importance of analysis remaining grounded within data (Reid, et al., 2005; Smith & Osborn, 2008) it seems appropriate that the data itself is foremost selected, formulated and narrated by the participant, with only minimal direction on the part of the interviewer.

Online methods of collecting qualitative data have been documented over the past decade though there are still a number of disagreements concerning the overall suitability of this method of data collection (Ayling & Mewse, 2009; Jowett, et al., 2011). Davis, et al., (2004) suggest that the potential for ambiguity is increased when using synchronous online interviews as instances of sarcasm or metaphor may be difficult to communicate adequately. Text based interviews may also present issues for conveying emotions as it lacks the usual forms of paralinguistic communication such as the tone and cadence of voice and body language. Despite this there are certain online paralinguistic entities, such as slang, abbreviations, emoticons and the use of capitalisation which participants may choose to use to convey emotion, emphasis and humour. Empathy however is

often difficult to convey as it must take the form of written empathic responses in lieu of intonation and body language. Empathic understanding may have been facilitated partially by my status as an insider, as participants may have expected me to appreciate and perhaps more easily comprehend certain aspects of their experiences. Indeed participants would often, upon finishing a typed response, close with "do you know what I mean?" or "you know how it is" or similar variations, providing both an opportunity to express empathy and understanding where appropriate and an opening to enquire further in certain instances.

A further issue when conducting online interviews concerns the flow of communication, which may be easily disrupted and may not follow the linear conventions of face-to-face communication. Davies, et al., (2004) have argued that this may result in a loss of meaning within the data. However I have found that this may not necessarily occur in all instances and may be highly variable depending on the interview topic, the individual being interviewed and the quality of the interaction between the interviewee and interviewer.

There are a number of practical issues which are commonly encountered when using online interview methods. Conversations are generally considerably slower, as typing a response is less spontaneous and more time consuming than speech. The result is that far more data can be gained in a much shorter time using face-to-face interviews than with online methods. Though this issue is offset somewhat by the fact that online interviews are easier to organize as individuals are not required to travel to the interview location. As typed responses may be less spontaneous than speech there is the potential for the loss of certain kinds of data as participants may take more time to formulate a response. It should be mentioned however that sufferers of SM may communicate primarily through the use of text in everyday situations (Viana, et al., 2009; Roe, 2011) and thus may be more comfortable and adept at written communication than other groups.

Despite the potential drawbacks and limitations of online interviews, which have been noted, the nature of the difficulty being studied made this method the most appropriate choice, as many participants would have been unable to communicate at all, or in a very restricted capacity, had face-to-face interviews been utilised.

### 3.3.3 Interview schedule & design

Three interview sessions took place with each of the six participants, with each interview taking approximately one hour. The interviews followed the biographic-narrative interview methods described by Wengraf (2001), modified slightly and altered to suit online interviewing. The initial interview session began with a single narrative question asking participants to describe the story of their life. The following narratives typically covered topics including when SM began, how it was experienced, what drove sufferers to seek help, and the eventual outcome of that endeavour, leading to the present day and perceptions of the future. Prompts were used in places and some questions were asked to probe further into specific topics. Both the first and second interview sessions explored the narrative accounts of participants. The third interview session took place after the initial transcripts had been read several times and preliminary themes had been identified. This interview incorporated in-depth semi-structured interview techniques, with questions tailored to specifically inquire about the individual's previous narrative account. This interview allowed participants to reflect on what had been said and provided an opportunity to discuss preliminary themes with participants themselves. The use of this member check, a qualitative error reduction technique used to improve the accuracy and validity of findings (Pope & Mays, 2006), facilitated a greater inter-subjective understanding between interviewer and interviewee and allowed for participants to give their own feedback on the appropriateness of the preliminary themes and the degree to which they captured the essence of their experiences.

### 3.3.4 Ethical issues

This study was conducted in accordance with the ethical guidelines of the British Psychological Society (Ethics Committee of the BPS, 2009) and approved by the School Research and Ethics Panel of the University of Huddersfield. Informed consent was gained from all participants prior to their taking part. Issues regarding consent, withdrawal, anonymity and participant wellbeing were covered within the initial consent and introduction forms. Participants were made aware that participation was voluntary and that they were free to withdraw from the study or terminate the interview at any time. At all times throughout the study the



interviewer attempted to be as responsive and attentive to participants as possible and to sensitively approach any topics which may have been potentially distressing. For example one participant, Mark, had lost both of his parents at a young age, during my interview with Mark we discussed to what degree he would be comfortable speaking about this topic. At various points with all participants I found it useful to inquire into how individuals were feeling in the here and now of the interview setting, while participants often replied that certain issues had conjured up various emotions, the overwhelming response among all participants was that it was a relief to talk about many of these issues and events, as one participant, Mark, stated after I inquired into how he felt:

Mark: It's ok, yeah I guess it's not nice to think about but it's something I don't get to talk about to anyone really. It's nice to have someone to talk to sometimes I feel like I could go a bit mad keeping it all in...

A number of other ethical considerations regarding the dynamics of power and the importance of empowering the voices of participants have been discussed in greater detail in previous sections.

### 3.3.5 Stages of analysis

Analysis progressed following the procedures documented by Smith & Osborn (2008) and Smith, et al. (2009). During the first phase of analysis the six transcripts were each read and reread a number of times. At this stage the objective was to dwell within the raw data and to empathetically understand the life-worlds of each participant. Some broad concepts were noted as emerging at this stage, including SM as loss, themes regarding the isolating effects of SM and themes relating to the narrative journeys of participants including the motivations for seeking help and the experience of doing so. In the second phase sections from the transcripts were commented upon and annotated, such as those which appeared to be significant within participant narratives or which appeared to capture or communicate some essence of the nature of SM. This included the process of recovery and thoughts and beliefs of participants regarding their interactions with the various health care services.

In the third phase various interpretative methods of identification were utilised, including abstraction, in which super-categorical and subordinate concepts, particularly those regarding psychological conceptualisations are formulated and considered, contextualization, by which the representations of abstraction are balanced against the person-in-context, and subsumption which involved the categorisation of super-ordinate and sub-ordinate themes (Smith, et al., 2009). At this stage emergent themes were noted. Both phase two and three were reiterative and fluid processes. Occasionally themes would be re-examined and placed within other themes or noted as potentially concerning aspects which might illustrate two distinct thematic entities. During this stage a third interview was conducted with participants which allowed for a discussion of the themes identified. This ensured that all participants were given the chance to comment on the appropriateness of the themes identified and to ensure participants that their data were being fairly represented. This was an important stage, not only in ensuring that this analysis was firmly grounded within the life-worlds of participants, but also as a response to the numerous historical studies which may have misrepresented SM and contributed to the continued misunderstandings and discongruity within the literature, which have only recently begun to be corrected (Roe, 2011).

Through the fourth stage of analysis the themes which emerged were grouped within the super-ordinate themes presented in the following analysis. Each theme within the analysis section is presented alongside a discussion of how these themes relate to existing psychological theory and literature.

### 3.3.6 Participants

Six individuals chose to take part in this research after responding to calls for participants which were directed at a number of online forums for sufferers of SM.

Sarah was 25 years old and had suffered from SM since her early teens. Sarah was diagnosed with SM at the age of 18 and had received brief cognitive-behavioural therapy. Her father was one of the few people she could communicate with freely.

Mark, 35, was the oldest participant to take part. Mark had experienced SM since childhood, and attributed its onset to the death of his parents. During his teens he

attended group therapy workshops for individuals with autism spectrum disorders, but left after finding them unhelpful. Mark stated that communication was limited to very close friends and some family members, but that he had been making steady improvements recently to try and overcome his difficulties.

Sam was 27 years old. Like Sarah he had received CBT for a number of years and had sporadically attended counselling sessions. For Sam speech was limited to occasions when he was with his parents or his sister.

Rose, currently 28, had suffered from SM since childhood but had been making progress in overcoming her difficulties. Like the other participants Rose only regularly spoke to close family, though Rose was also able to respond verbally to other individuals in a limited fashion, such as answering questions or saying short phrases.

Mara, 24, had experience SM since her mid teens but wasn't diagnosed until she was 21 after which she received counselling for a number of years. The only individual she could speak to comfortably was her mother.

May was 30 years old and had experienced SM since childhood, though she was only recently diagnosed and hoped to attend counselling or therapy in the near future. May was rarely able to speak to anyone, but had a number of friends online with whom she could communicate.

My own experience with SM began at around the age of 12, prior to this I had been able to communicate freely in all situations. From the age of 12 I found it increasingly difficult to speak, first at school, then with friends and eventually with family until the only person I could speak to was my mother. In all other situations and with all other people no matter how much I wished to speak I found that I could not, and my interactions with others became limited to nods, shrugs and occasionally a quietly mumbled "mhm". Only in the last few years have I begun to regain a sense of normality in life and, though there are still many situations in which I feel there is room for improvement, I can once again (usually) speak.

# Chapter 4: Findings & Discussion

This section presents the themes identified from participant narratives (See table 3). Excerpts from participant transcripts and my own reflective narrative are included throughout. Each theme within this section is presented alongside a discussion of relevant psychological theory and literature. The themes within explore diverse aspects of SM. These include considerations of the embodied experiences of sufferers and the impact of SM upon their sense of self-hood and their emotional experiences. Also discussed are the ways in which SM has impacted the lives of individuals both in day-to-day situations and over the course of their lives, as well as how SM has affected sufferers' social relationships.

Table 3. Master themes and subthemes identified from participant transcripts

Master Theme	Sub-Theme
<b>Master Theme 1: Selective mutism as loss</b>	<ul style="list-style-type: none"> <li>▪ Trapped voices</li> <li>▪ The habituation to silence</li> <li>▪ Lost Hope</li> </ul>
<b>Master Theme 2: Selective mutism and isolation</b>	<ul style="list-style-type: none"> <li>▪ Being alone</li> <li>▪ Falling out of the world</li> </ul>
<b>Master Theme 3: Journeys towards recovery</b>	<ul style="list-style-type: none"> <li>▪ Regret and resolve</li> <li>▪ Seeking help</li> <li>▪ The influence of diagnosis</li> </ul>
<b>Master Theme 4: Experiences of therapy</b>	<ul style="list-style-type: none"> <li>▪ The therapeutic relationship</li> <li>▪ Thinking a way out</li> </ul>
<b>Master Theme 5: Towards the future</b>	<ul style="list-style-type: none"> <li>▪ Towards the future</li> </ul>

## 4.1 Selective Mutism as Loss

The themes within this section explore SM as an experience of loss. The first theme, trapped voices, explores the embodied experience of feeling as if one has lost control of one's own voice. The second theme, the habituation to silence, explores the process of sense making in which participants engaged as they attempted to make sense of this loss, exploring the ways in which silence and isolation created feedback loops, reinforcing the silence of SM. The final sub-theme, lost hope, explores how the feelings of loss regarding both the embodied experience of SM and the existing realities of individuals' lives contributed to an overall sense of futility and hopelessness.

### 4.1.1 Trapped Voices

This theme explores the felt sense of vocal imotility described by all participants in this study. Participants often found it difficult to convey the embodied experience of SM. Several individuals employed language which positioned SM as if it were a mechanism or process capable of wresting control from the individual, resulting in the felt loss of one's own voice:

Mara: It's just horrible... It's hard to describe without sounding a bit nuts, it's like you know what you want to say, but something's missing. I could be sat with my family and I have something I want to say but it's as if something grabs the words away between my mind and my mouth.

This sense of being robbed of one's own voice was consistent between participants often leading to a felt sense of failure. While many individuals with SM are able to speak in some, usually very limited circumstances, for Sarah this division served only to evoke a greater sense of disappointment in those instances where speech was difficult:

Sarah: The thing is I know I can talk because I talk to my dad, I don't have to try it's just natural I open my mouth and words come out I say what I want you don't even really think about it, just normal talking. I think that makes it worse because I know something is wrong and I know how it's supposed to feel.

Sarah's description evokes two contrasting modes of identifying with one's own voice. One in which speech occurs naturally and without effort and a second sense in which one feels unable to speak and yet is acutely aware of this uncomfortable breakdown of the lived-body experience. Husserl (1989) described two aspects of the mind body-schema, the physical body, Körper and the lived body, Leib. Husserl believed that the lived body is largely transparent to our senses if we are absorbed within life. As Sarah described, conversation is normally automatic and spontaneous occurring without strenuous effort. In participant descriptions of SM however a sense of estrangement is felt regarding control over one's own voice, as this sense of a controlled body breaks down. As Mark also described:

Mark: It's as if something's gone wrong in my brain but at the same time I know that the part that's me is working fine, if that makes sense? Like I know how to speak and I know what to say, but it just won't... do anything.

This breakdown, and the shift in experience of the body experienced as self (I) and object (it) is clearly illustrated in Mark's account. These descriptions diverge considerably from research which has suggested that SM may indicate an inhibited temperament (Moldan, 2005) as individuals clearly expressed their desire to speak and had contributions to make to conversations. Indeed, if individuals were inhibited then remaining silent could be expected to provide relief rather than distress, yet this was not the case as 'remaining silent' was felt to be imposed upon these individuals rather than being an accepted behaviour. The result for some participants over this felt loss of vocal control was frustration while for others it was a profound sense of disappointment and failure:

Rose: It makes you feel useless, it's just talking and I couldn't do it. It doesn't make any sense you just feel stupid.

Sam: I think everyone gets it sometimes you think oh I wish I'd said this but it's too late. Imagine that all the time, you wish you'd said anything but you couldn't. I just want to do something but there's nothing that helps.

Such a perspective of one's own behaviour demonstrates that these individuals did not accept SM as part of their identity rather SM was felt to impose itself upon them in painful and frustrating ways. These findings match those of Roe (2011) who found that many of the children within her study reported feelings of frustration and sadness surrounding their inability to speak. There exist no statements by adults regarding the emotional effects of SM within the literature, and very few concerning children. Unfortunately this has meant that the desire to speak has been overlooked in almost all existing studies despite this potentially difficult aspect of living with SM being profoundly felt. Whilst some studies have portrayed sufferers of SM as shy and emotionally and socially inhibited (Moldan, 2005; Beidel, et al., 2012) this was not the impression given by participants. While throughout each participant's narrative there was a sombre tone as a number of difficult and emotive topics were discussed, I found all participants to be sociable and talkative, friendly and at times displaying a thoughtful humour. I would not have described these participants as nervous, anxious, introverted, shy or lacking in confidence, yet this is the image presented almost exclusively within the literature. Only Roe (2011) upon asking children about their own self perceptions found individuals to possess, or perceive themselves to possess, characteristics such as talkativeness and friendliness. While this may be in part due the nature of online interviews and the use of written communication it may also be due to the lack of perceptual data; I could not see the silence of participants. Had these interviews been undertaken face-to-face I, as the majority of the existing literature has done, may have considered these individuals to have appeared withdrawn and inhibited. This possible misrepresentation, a result of the outward presentation of silence, was one which several participants struggled with:

Sam: I know it's awkward for people, I know they look at me and think I'm shy and a bit weird, you know people say "there's Sam, he doesn't say a lot" and straight away I know that sets me up as shy and quiet. Well of course I seem quiet, I can't talk but it doesn't mean I don't want to.

Sarah also succinctly described the strangely felt disparity between her felt identity and her outward presentation:

Sarah: I suppose it's like I'm an outgoing person trapped in a shy person's body. I'd probably felt better if I felt shy, haha.

Again there is a sense of being trapped, as silence was a state felt to be unnatural, going against the desires of sufferers themselves. Alm & Frodi (2008) explored the experiences of individuals who perceived themselves to be shy finding that they described feelings of discomfort as arising from the contexts in which they found themselves, such as when speaking in public, at parties, in crowds or around figures of authority. This diverges from SM as silence may not always be accompanied by a felt sense of shyness arising from the social context. Although outwardly the resulting avoidant and quiet behaviours may appear almost identical to observers, the embodied experience may be quite different, as Sam described when discussing his experiences of completing tasks assigned in therapy:

Sam: I remember one exercise was to go and walk around a shopping centre. But crowds and things don't bother me I could be in the most crowded place on earth and I wouldn't care. But as soon as you ask me to say something then I get nervous because I know I won't be able to and then I just feel stupid. I think people just think well you must be a shy quiet person if you don't talk otherwise you'd talk, you know?

The divide between a felt sense of self and an uncontrollable silence was not total however. As documented within the literature, children with SM often speak comfortably to parents (Ford, et al., 1998, Roe, 2011). The adult participants in this study could similarly communicate with specific individuals, again this was primarily parents, but also extended for some individuals to close friends and partners. Participants often described these interactions as being the only times when they truly felt as if they were themselves:

Sarah: When I talk to my dad it's fine I'm back to how I used to be before [the onset of SM]. That's who I am who I used to be all the time. I chat I make jokes, I'll sit and talk for hours, but any other time it's like that's stuck behind something else. I don't know why, maybe it's because I've always talked to my dad but I used to talk to other people like family who I can't talk to now so I dunno.



As Sarah described, the nature of SM may result in confusion as the progression of the difficulty seems unrelated to any conscious effort to remain silent, affecting some relationships where speech once occurred and yet not others. The existing literature has provided only tentative explanations as to why speech occurs in some instances. Initially this was explained as a result of oppositional behaviour with silence being a chosen act on the part of the child. A further explanation suggested that children with SM were attempting to control impulsive behaviours by remaining silent as a means of self-regulation (Moldan, 2005). The accounts by participants here however do not suggest a conscious regulation, nor any impulsive behaviours occurring in the instances where speech was possible, on the contrary, occasions where speech had been possible were described as the only instances in which a sense of normality was achieved.

Mara described how the increasing severity of her SM caused relationships to break down until the only person Mara was still able to speak to was her mother. Mara makes sense of this by suggesting that some bonds, such as those with parents may sustain and preserve speech in spite of SM:

Mara: As it gets worse it's like it happens to everyone, to people I could talk to before, for a long time the only person I could talk to was my mother. I don't know why, I can't imagine not being able to talk to her, I think without that, it's like, I know she'll always be there and no matter how bad it might have gotten I'd still have that. So like still have that proof that I am a normal person underneath.

Research has typically focused on relationships which are detrimentally affected by SM, rather than those which are preserved in spite of this difficulty. Moldan (2005) reported that children with SM were, while at home with parents, overly excited, overly silly and prone to tantrums and thus selective mutism may be a manner of controlling such inappropriate behaviours in situations where they are unacceptable. However no comparison between 'overly' excited and typical childish excitement was provided. Such explanations seem inappropriate in explaining the experiences of adults with SM, as they fail to reflect the experiences of sufferers described here, in which the instances where speech still occurred were the only ones in which individuals were able to achieve a sense of

normality. Perhaps, as Mara supposed, there are some relationships which are immune to the effects of SM, such as the close bond between a parent and child. There may be no further need to problematize such relationships in an attempt to impose theoretical conceptualisations of SM upon the normal human relationships which remain unaffected.

My own experience of SM matched closely with those of the other participants, there was a point when I too was only able to speak to close family. Over time I was able to slowly expand the group of people I could speak to, first to close friends and eventually to numerous contexts, though the process was slow and took many years. The following passage detailed my own attempt to describe what it felt like to suffer from selective mutism. Similarly to Sam and Sarah, I recalled the distressing results of remaining silent:

Aaron: Imagine you're with a group of people, you have something to add, but something stops you from saying it. You begin to tense up, trying to mentally force the words you want to say out of your mouth. You try reciting what you want to say in your head, willing yourself to say something, anything, but you can't and by now the conversation has moved on. You start to beat yourself up about it as you know the silence is awkward and you begin to feel more and more uncomfortable. Even though you wish you could talk, in the future, you'll avoid those situations if you can, because of how distressing the failure of silence can be.

#### 4.1.2 The Habituation to Silence

This theme explores participant narratives which gave structure to the progression of SM. The onset of SM was for many participants vague and difficult to pinpoint though attempts at explanation were made by all participants. Models concerning the onset, progression and reinforcement of SM, as discussed in chapter 2, are often un-detailed, with factors such as anxiety and avoidance having been extrapolated from behavioural observations of young children. These accounts by participants concerning their own experiences and their attempts at making sense of them may shed some light on the more detailed complexities underlying SM.

While the events which were positioned as causal by participants varied, a common underlying theme was a felt loss of belonging, as situations arose which denied the individual's own voice:

Sarah: I was bullied a lot, I must have been about ten or eleven so I'd just changed schools I think that's when it started, but it isn't that I chose to stop talking it sort of just happened. I didn't have anyone to talk to and people made fun of me if I said anything anyway...

Rose had also experienced bullying while at school and similarly viewed such events as causal, though even to Rose herself this explanation seemed insufficient, as it failed to explain why she was affected by SM in other contexts:

Rose: I think that because I didn't have anyone to talk to it sort of spiralled from there, but it doesn't make sense because I can't talk to my family and other people are bullied and they don't stop being able to talk.

While bullying has been investigated to a degree within the SM literature it has typically been viewed as a result of the child already having SM (Cunningham, et al., 2004). Several researchers however have suggested that children with SM are not bullied on average more than other children (Kumpulainen, 1998; Pellegrini, et al., 1999). The role of victimisation has received little attention beyond this. From several of the narratives explored here however, these experiences were often central to attempts at understanding the origins of SM. Though, as Rose explained, the question of why may remain difficult to answer.

Mark attributed SM to the loss of his parents, though he admitted that he recalls little about those events, he had attempted to make sense of events from the information he had been given by other family members:

Mark: When I was 5 I went to live with my dad's brother and his family. My aunt told me that I was quiet but I don't think it was like now, I remember playing with my cousins and other kids and stuff. I think maybe there was always a feeling that, well not that I didn't belong, but sort of that, I don't know. Maybe that somehow led to having selective mutism in a way. It's not something you notice happening I don't think, you know?

Throughout participant narratives concerning the onset of SM there was a sense of uncertainty, with SM typically being viewed as a slow progression from an initial isolating event. Mara provided an evocative metaphor for the progression of SM:

Mara: It's as if, at first it makes sense, like there's a crack in a wall and it gets a bit worse but you don't really notice, so like I could talk to my friends at school, but around other kids I'd keep quiet, but then friends move away or just get more distant or whatever and the cracks get bigger and you kind of start to notice maybe this is a problem but you just keep going. Then one day you wake up and realise the house has collapsed.

How do these 'cracks' appear and what causes this habituation towards silence? As always the theories which have been put forth typically concern young children under five years and regularly fail to account for contextual reinforcers or the life circumstances in which individuals are situated. Mara was able to pinpoint several events, such as the loss of friends and her difficulties making new ones which contributed to SM and also to her opportunities to speak with others. Throughout participant narratives a number of diverse factors which influenced the worsening of SM were described as creating reinforcing spirals, as in Rose and Sarah's accounts. Typically these concerned the loss of opportunities for social interactions to occur, the loss of the ability to speak comfortably and the loss, or perceived loss, of the actual ability to converse, leading to a continual ingraining of silence.

Sarah: It's like a catch 22 because I don't have anyone to talk to any more so I can't you know... practice talking to people. I'm 25 years old so what do I do, I can't go for a job interview and say hi sorry but I find it really hard to talk to people but this might be good practice. Or do that at a lunch with friends or anywhere, because I don't have any. It's just going round in circles.

Again, there is a sense of a futile spiralling, as the inability to speak limits social interactions, and reduced social interactions reduce opportunities to speak. Mark expressed how his own experiences of having lived with SM had contributed to his silence, as the poverty of an unlived life distanced him from others:

Mark: Sometimes I feel like I don't even know how to talk any more, I can sit in a room where people are talking about work or what they did last night and there's just nothing I have to say even if I wanted to. Maybe if the conversation was about where you were never even able to talk to people and were living a depressed and lonely life then I'd have something to add, haha.

Suffering from SM may, as in Mark's experience, lead to a felt sense that one has little in common with others such that even if one were not suffering from SM then silence would nevertheless be the outcome. This sense of no longer being part of the world is discussed in further detail in relation to isolation later in this chapter, though this may also play its part in the self-reinforcing habituation to silence.

Sam described how SM led him to feel excluded by others even where considerable effort had been made to reintegrate and overcome his own difficulties. An experience which for Sam ultimately led to a further sense of hopelessness and resignation:

Sam: I tried going to college, it was something we tried to sort of build up to when I was going there [therapy] every week, but it wasn't a nice experience at all. I said a few things on the first day but it's not enough, you know, it's not normal, I don't think people really give you a chance. I understand it but it's not helpful for someone who's trying to get through something like SM. I was a lot younger then but it still sort of leaves you thinking you know... what's the point.

All existing research has focused on primary school aged children with SM, with several interventions having been documented which attempt to increase children's interactions at school with peers and teachers, though this is typically positioned as an attempt to overcome the inherent disability of the child rather than alter any potential contextual reinforcers regarding the school or classroom environments. Models and theories of SM which fail to take into account such contextual influences may commit what Dannefer (1984) described as an ontogenetic fallacy, as social phenomena are taken to reflect characteristics of the individual rather than context or environment they are situated within. Sam's

account describes one such constitutive social phenomena as he recounts his experience of trying to integrate with his peers at college. While his difficulty is partly a result of SM it is the combined interaction of this specific context and the expectations and behaviours of those within it, in tandem with Sam's own struggle with SM, which influence the outcome. As numerous sociological and developmental studies have found, integration at college, school and work play important roles in the formation of our identities, self-esteem and social worth (Gaertner & Dovidio, 2000; Kaufman & Feldman 2004). Individuals are typically quick to form friendships in new situations such as these and as groups are formed and a sense of belonging achieved so too is a sense that one is progressing and growing (Deci, et al., 2006), yet this may be denied for those with SM.

During my own time at school and college I experienced something similar and though I felt accepted, in a way, I also always felt separate and distant as I was never able to interact on any meaningful level:

Aaron: I recall at college being in a very small class of about 10 or so individuals. We would all have lunch together, but I was never able to say anything. I was just there. My input was limited to nods and shrugs. It was intensely lonely to the point where it is still somewhat painful to recall.

#### 4.1.3 Lost Hope

Hopelessness was a core feature of participant narratives. As the possibility for change diminished, hopelessness took its place. Questions of how one might change or overcome SM were similarly overtaken by a sense of frustration and a need to escape the hopelessness which participants encountered. Sam described one method of escaping the difficult reality of his life and the hopelessness of SM:

Sam: I used to sleep a lot, it's like fast forward for life, I mean what was I gonna miss? Being alone and depressed. Sometimes I'd dream I had a life and had friends and that was better than being awake. But then sometimes I'd wake up and it'd sort of hit me that my life isn't like that so it didn't always help.

Sam's explanation creates a stark picture of his experience of avoiding the present through sleep, which he describes as a method of fast-forwarding life. His inability to always live in the present arose from the difficult reality of his situation, of his isolation and the feeling that he was missing out on life and nothing could be done. Through dreams he achieves not only respite from the pain of the present but a substitution for it, for in dreams Sam did not have to suffer from selective mutism.

There is an extensive cultural history regarding the catharsis of dreams, though as Sam describes, such fantasies may also serve as a mirror to reality, making the waking world appear all the more painful in comparison. Sam's experience shares many similarities with phenomenological accounts of depression, such as a loss of affectivity, as the world and everything within it becomes meaningless, and a profound disconnect becomes felt (Aho, 2013). For Sam, sleep provided a temporary respite from life with SM. However the hopelessness arising from the experience of SM may for some cause thoughts to turn towards a more permanent form of relief at times:

Sarah: You get so frustrated because you don't know what to do and it all just feels hopeless. I did think about suicide in the past, it's like there's no way out when you can't even ask for help or explain what's wrong. For a long time I didn't even know what was wrong or that it had a name or anything, you just feel like nothing is going to get better. When you start thinking about the future with nothing ever getting better that can really get to you... you don't wanna be there when that future happens.

Sarah stated that after her brief therapy and her continued efforts to overcome the difficulties of SM that she is no longer confronted with thoughts of suicide. In this passage however Sarah reflects back on occasions when the future seemed bleak and improvement appeared impossible. Causing further difficulty was that, until her diagnosis at the age of 18 she was not aware that what she was suffering from was a recognised difficulty.

May similarly described how the experience of SM denied any positive affect and spoke of the day to day struggles she faced in life:

May: You just get up every morning and try making it through the day it's not a nice way to live. Not talking stops you from doing any of the things that might let you feel happy or good about anything because how can you be?

For Heidegger (1927) feelings could not be understood by dividing them into the separate categories of 'inner states' and 'outer realities' as the two are inherently entwined. Thus, and as has been argued, the depressed state of being cannot be altered when subject to introspection alone (Arnold-Baker, 2005). It may demand that one alters one's experience of Being in the world, which is always contextually bound. Depression however can often negate such a possibility, as it diminishes one's sense of optimism for the future, leading to inertia and despair (Yalom 1980; Clarke & Kissane, 2002). This was reflected in participants' accounts as they described feeling as if there was 'no way out' and that nothing could be done to alleviate their difficulties. Depression in these instances was felt to result from the impact and influence of SM, it transcended the mood of depression to become the truth of a paralysing reality. As Mara explains, the possibility of anything positive was felt to be completely denied by the silence of SM. She later explained this in terms of a shrinking world, whereby painful externalities were avoided and a sense of hopelessness was ever present:

Mara: It affects everything. If you go outside you feel stupid because you're alone, you feel so... childish I guess because you can't do normal things people do, so you try to avoid all the things that make you feel bad about yourself and the things you can't do until there's nothing left and that's even worse.

The impossibility of change which encapsulates the experience of hopelessness was also echoed by Rose, who described how her search for information served to reinforce the feeling that it was too late to change:

Rose: It felt like it was never going to get better. I remember reading online about it and it's all about children and you think well, it's supposed to be gone by now then isn't it. It just makes you feel horrible like it's too late so why even bother.



As discussed, SM is often regarded as a disorder of childhood with only sporadic mention of adult sufferers. Information available online is often orientated towards the parents of child sufferers. From my own experience interacting with forum communities of adult sufferers it is not uncommon to see sufferers asking, in response to having looked for information about SM, if it is 'normal' to be suffering from SM as an adult. As with Rose's experience, this may potentially create an additional layer of painful thoughts, further lowering one's self-esteem and self-efficacy. A lack of information regarding adult sufferers may play a role in dissuading individuals from seeking help and may have an overall disempowering effect upon adult sufferers (Corrigan, et al, 2009).

Depression is often presented within the SM literature as a co-morbid disorder suffered alongside SM (Bergman, et al., 2002; Sharp, et al., 2007). As participant accounts have shown, the experience of depression and selective mutism are interwoven. To label feelings of despair and hopelessness as an additional diagnostic categorisation is to represent these facets of experiencing SM as secondary, de-legitimising depression as a natural response to isolation, fear, frustration and silence. As Lilienfeld, et al., (1994) argued, the use of such imprecise language may lead to similarly imprecise thinking. If depression is to be disentangled from SM to any degree then it may be more accurate to refer to depression as a concomitant disorder rather than as co-morbid. A complete understanding of the phenomenology of SM requires acknowledgment that for some sufferers depression is inseparable from their experiences of SM. Silence and isolation are inherently painful when they constitute the majority of one's life and to view them as a maladaptive states of being, which can be separately categorised, serves only to deny the legitimacy of such feelings. Attempts to delineate experiences into imprecise diagnostic categories, which may only be conceptually separable, serves only to increase the imprecision of those categories diminishing our understanding of the reality of human suffering.

## 4.2 Selective Mutism and Isolation

The themes covered within this section explore participants' experiences of isolation, including both the experience of social isolation and a far deeper sense of existential isolation and the profound sense of no longer being in life.

### 4.2.1 Being Alone

Loneliness was a theme which pervaded participants' experiences of SM on multiple levels. A deep sense of interpersonal isolation was felt by participants as their silence rendered meaningful social interactions difficult or impossible. Both the silence of SM and the lack of meaningful social interactions were experienced by participants as continual reinforcers of social isolation from which no relief seemed possible. For some, prolonged social isolation resulted in a profoundly disconnected experience, as individuals felt their isolation had irrevocably altered their lives to such a degree that they would never be able to reconnect with others or feel part of the world again. This second form of existential isolation caused some participants to recall instances of derealisation and depersonalisation as the experienced gulf between themselves and the world increased. May described how SM engendered a steadily worsening social isolation:

May: It really makes you feel useless. You feel bad about not talking so you avoid it, then you avoid going out or doing anything and you feel bad about that too. I get annoyed with myself, like you shout at yourself in your own head, but at the same time I don't know what I'm supposed to do...

May's account conjures up a profound a sense of futility as she berates herself for her feelings of powerlessness, of being 'useless' to alter the course of a self-reinforcing isolation. May describes how avoidance led to isolation, and isolation excluded future possibilities for contact until May's world withered away and she was left shouting in her own mind. The notion of mentally shouting at one's self was mentioned over the course of the interviews by several participants, and seemed to encapsulate the frustration inherent in losing a sense of control over one's own voice and of losing the social aspects of life. Sam described how

observing the social interactions of others served to highlight his own sense of unbelonging:

Sam: It's hard to see people living life normally because you realise how weird your life is. Even something like seeing a group of people talking, like, everything just collapses and there I am alone and.. well that's it, I'm alone. It's like in the pit of your stomach you feel it you want to shout for help but you can't. Even if you could what could anyone do.

Sam describes his sense of alienation as particularly difficult and which may be brought about by observing commonplace every-day events and the interactions of others. Sam's experience seems to reflect something of Heidegger's concept of the uncanny (1927), the uncomfortable sensation of strangeness we feel upon the loss of familiarity with our sense of being. Sam's distress is described as a product of the division between how things ought to be, and may be for others, and how his own experience is shaped by isolation.

In some instances isolation may result from an attempt to protect the feelings of others, as Sarah describes when recounting her difficulties speaking with her father about SM:

Sarah: Yeah, I could still talk to my dad. I could have said something, told him how I felt or that it was really affecting me. But I couldn't upset him or make him feel like it was his fault or anything which I think he would have on some level you know.

During the period of Sarah's life in which she suffered most severely from SM her father was the only person with whom she felt comfortable speaking, yet even this freedom was limited. In the midst of Sarah's own suffering there remained a desire to protect the feelings of others, though this too engendered yet further isolation. This was the only instance in which any participant spoke of isolation in tandem with choice, though even in this instance the notion of choice may be ambiguous, as Sarah's final line makes it clear that the potential for upsetting her father excluded the possibility for her to talk to him about her difficulties with SM.

A second factor to which people attributed their isolation were the actions of others. Mara described how she felt ignored as few individuals attempted to communicate with her.

Mara: It's hard because you start thinking about why people don't talk to you and why they just ignore you, I know on one hand it's because of SM and it's gonna be hard to keep talking to someone who can't say a lot. But when no one even tries how do you explain that? So you do start to think all these negative things because you try and fill in the blanks for why people ignored me.

Mara's attempts to make sense of this, to 'fill in the blanks', resulted in several difficult and anxiety provoking thoughts:

Mara: You end up thinking there must be something really wrong with you, it's everything, you worry even more about not being able to talk, then like how you look or dress or even silly things like just the way you stand and you know it's silly in a way. How else do you explain it though?

Rose similarly described how other individuals had seemingly ignored her, attributing this as Mara did partially to her own difficulties with SM, but also to a felt sense of stigmatisation. Rose also described how these experiences were felt to restrict her own attempts at overcoming SM:

Rose: A lot of the time it seemed like no one cared. People kind of ignore you.

Aaron: Why do you think they ignore you?

Rose: Because people aren't very nice. I can write, type, even sometimes I can manage a few words even if it's just whispers, if anyone ever bothered to care that someone they see every day was alone, well.. I don't know. I know having SM is part of the problem but how am I meant to try talking to people when they don't give you the chance?

These accounts illustrate the complex relationship between SM and anxiety, resulting from the social isolation faced by sufferers. As SM leads almost

inexorably towards social isolation questions may arise in the minds of sufferers as to why they are seemingly ignored. As SM itself may be felt to be insufficient in explaining why others fail to attempt to initiate contact, the result may be a process of sense making which leads towards a reinforcing spiral of avoidance and isolation, as others become viewed as hostile, uncaring and judgemental.

#### 4.2.2 Falling out of the World

Sustained social isolation for some seemed to eventually lead to a deep sense of existential isolation. Existential isolation, unlike social isolation, is a felt loss of coherence with the world itself as if one were existing separately from the world or viewing it from afar (Yalom, 1980). Existential isolation shares similarities with derealisation and depersonalisation, as one begins to feel as if they are not entirely experiencing reality, but only its shade (Medford, 2012). Mara's experience of the socially isolating effects of SM seemed to further encompass this sphere of isolation:

Mara: It's as if your whole world is just you, in your head in a little bubble. You don't have any of the everyday normal stuff that people have so it's like everything goes on around you and you're just stuck.

The experience of feeling dissociated from the wider world was also experienced in other ways. Sam described a line of thought which led him to compare his own sense of isolation to that experienced by prisoners, encapsulating the sense of unfairness Sam felt regarding his situation:

Sam: You feel like you're going crazy. I remember having weird thoughts like I'd probably be happier in prison, I could deal with that, it wouldn't even be a punishment because that's really no different from my life now, I'd at least be around people. Then you sort of catch yourself thinking these things and the sane part of your brain reminds you that's insane.

An unlikely source of stigmatization appears to influence Sam's thoughts regarding isolation. Incarcerated criminals are isolated from the outside world as a form of punishment, yet Sam experiences isolation by virtue of suffering from SM. Although Sam admonishes himself, stating that such thoughts are strange or

crazy, his comparison does not seem entirely inapt; prison bars may provide a more visceral image but a no less potent source of isolation than SM.

While we may all experience isolation at various points within our lives the potential to overcome isolating experiences is usually not outright denied, we may turn to family, loved ones or friends to remedy loneliness. For sufferers of SM isolation permeates the world on a far deeper level, not only is social isolation a reality for many sufferers but the possibility of overcoming it is further denied by the silence of SM. Speech is the manner by which we can transcend the isolation inherent in our existence and reach out to touch the worlds of others, through speech we assert ourselves as cohabitants of a shared world and through which we might achieve a sense of belonging. The denial of communication caused by SM may however create a seemingly unbridgeable gulf between the world of others and one's self, as Sarah described:

Sarah: Sometimes it's sort of like you've fallen out of the world, like normal life is just so far away. Like, what do I have in common with people any more, what would I even have to say to them...

This aspect of SM has received scant attention within the literature despite the associated thoughts and existing realities which pertain to isolation being so central to the experience of SM. While such a felt gulf exists within the lives of sufferers, overcoming SM may indeed be unlikely, yet there may also occur a stage in which, despite the devastating isolation caused by SM, a sense of resolve can emerge.

## **4.3 Journeys Towards Recovery**

The themes within this section explore participant journeys, including motivations for seeking help, how individuals overcame the practical difficulties imposed by SM and finally the effects of diagnosis for participants.

### **4.3.1 Regret & Resolve**

Regret is a powerful negative reaction to our inability to alter the past and the belief that, if things had been otherwise, they would have been better. For several participants feelings of regret and guilt shaped their experiences and their

orientations towards the future. For some, feelings of regret engendered a determination to change while for others the painful effects of regret furthered feelings of hopelessness rendering imagined futures bleak and fatalistic.

Sarah described the origins of a painful source of reoccurring regret which acted as a primary motivation for overcoming SM:

Sarah: When I was 17 my grandma died and other than my dad she was the only person who really talked to me, sometimes we'd just sit in the garden and she'd talk to me about plants or what she'd done that week or watched on tv. I'd just nod and smile but it was nice to be talked to like I was normal again... I know she wanted me to talk and I wish I'd been able to say something too. I felt bad about that for a long time and I still do. It's like... SM takes people away even when they're there. And it takes me away from them. You can't really live with SM or it'll take everyone away from you, I think. It made me realise it wasn't just going to get better on its own.

For Sarah, the death of her grandmother caused a deeper awareness of the effects of her silence, as just as death takes people from us, so too does the silence of SM. Death is the most powerful finality we encounter in our lives as it offers little reconciliation, for it denies any possibility to atone for past regrets. Marijo (2004) suggests that the most powerful and long lasting sources of regret are those which arise from a sense of betraying one's self, leading to painfully experienced existential guilt. As discussed in previous sections, a core theme pervading the experience of SM is the sense that one is not truly able to be one's self. The result may be what May (1983) described as a feeling that one had forfeited one's own potentiality.

While significant research has focused on the negative implications of existential regret (Marijo, 2004) and the possible neurotic responses to intensely felt regret (Zeelenberg, et al., 2000) there exists little research concerning the way in which regret may facilitate an increased determination to change. Sarah's response to a deeply felt sense of regret was a renewed effort to overcome SM.

Mara similarly experienced an intensely felt regret concerning the loss of contact with her family:

Mara: I didn't really see my family much, sometimes at birthdays, but even then they didn't really talk to me because they didn't expect me to say anything back. There's no good way of dealing with it because if I'm there I feel bad because I can't talk and if I just avoid those times then I feel bad for missing them. I miss them no matter what I do really...

Mara described how the two options available to her, silence and avoidance, both caused a feeling of missed opportunity. Social relationships were often discussed by participants as being diminished by SM, with the potential for meaningful social interactions with family and friends being denied causing further disappointment and regret. Morrison, et al. (2012) have suggested that social regrets, which are among the most long lasting and intensely felt regrets, affect us so deeply because they threaten our sense of belonging. The need to belong is an influential drive in human life and the threat, or reality as may be the case with SM, of social exclusion may powerfully influence an individual's mental and physical health (Cacioppo & Hawkley, 2009; Morrison, et al. 2012). In the face of social regret individuals may employ direct or symbolic efforts to regain a felt sense of belonging. For the participants in this study this often became manifest through an effort to seek help to overcome SM so that such regrets might be avoided in the future:

Mark: It's like you don't want to think about it and all the things that you haven't done or been able to do because of SM. [...] It's only now that I've tried getting help because I can't go on like this, so I have to do something...

Rose: It was hard for a long time looking back at my life and the things I'd missed. It gets to the point where you just can't keep going like that and you just have to do something, going to the doctors and saying "I can't talk, help" (or writing it) is hard to do but the alternative of doing nothing is even worse.



For others regret seemed to obscure almost any potential for recovery, extending into imagined futures which became as bleak as experiences of the past:

Sam: I mean, what do I have to look forward to? Because it never feels like it's going to get better. Sometimes I think what will it be like in 5 years or 10 years or even longer and what will have changed then? More things I've missed out on, just wasted time..

As Sam explains, the painful effects of SM may be cumulative as more time passes without recovery more of life is 'lost' to SM. Although Sam had received cognitive-behavioural therapy for several years he expressed that he felt little had changed, later in the interview he described his own feelings of guilt, as he considered the failure of therapy, and the failure of recovery, to be his own fault:

Sam: I think they [therapists] just get frustrated and tired of me. I understand it though. I know it's my fault because only I can make myself talk but I don't know how. It's like.. all those years gone because I can't talk, no friends, no work, no education, no money...

For some, the reaction to guilt may be a relinquishment of hope. This mirrors several responses to existential regret which have been documented within the literature whereby past events may evoke a paralysing sense of resignation from which individuals feel powerless to alter the future (Yalom, 1980; Marijo, 2004). Although Sam seemed deeply affected by the effects of regret he found meaning in yet another imagined future in which he was no longer affected by SM:

Sam: I kind of think of it this way, maybe one day I'll be better, I'll be happy and I'll be able to talk and then I'll look back and though it's still my life it'll be better because it'll have gotten me to where I am, if that makes sense. I still really hope that will happen.

I too have experienced regrets similar to those shared by these individuals; guilt that I was never able to speak to family members now departed, regret that too many years were spent silently and too many opportunities missed. Just as Sam envisioned a future in which achieving a better life could make the journey with SM worthwhile perhaps this research is, in part, my own attempt at finding

meaning from the regret of selective mutism. As Jung (1963, p.340) wrote, "Meaning makes a great many things endurable - perhaps everything."

#### 4.3.2 Seeking Help

A significant event within participant narratives surrounded the task of overcoming the silence of SM in order to seek help. In part this was described as a practical problem, with individuals employing various non-verbal means to convey their distress and difficulties to others. This task also required some individuals to overcome their fears concerning rejection, dismissal and stigmatisation. The initial instigating experience which drove participants to seek help was often described as a point of realisation concerning the severity of SM and its impact on one's life, as Mark described:

Mark: It's like, you start to realise it's eating up your whole life. If I knew what I was supposed to do or how I could have done it then I would have by now. Actually getting help is another problem because that seemed impossible too, in the end I wrote a note saying everything I wanted to say and took that with me to my doctor. It felt silly to do, but I think it let them understand how bad my problems were.

Mark describes feelings of confusion and desperation regarding what he was supposed to do to overcome SM. There is an underlying impression of not being good enough to overcome these difficulties alone in Mark's account. Confronting this realisation served as a powerful motivator driving Mark to seek answers and help. Practical difficulties surrounding help seeking were also encountered by Mark and while he eventually overcame these issues through written communication this method itself served as yet another reminder of the abnormality of Mark's situation.

Mark's experience closely mirrors my own, as I too wrote about my experience of SM in a note which I handed to my GP. After handing it over I recall an overwhelming sense of sadness, as if I had just handed over a confession of my failures. I don't recall her reaction, I was far too busy imagining what her reaction might be to have paid attention. That event ultimately led me towards the path of overcoming my selective mutism. Had my GP at the time been of a less

sympathetic and kindly nature then that note would almost certainly have remained with me. Unfortunately not all such disclosures are met with understanding, as Mara described:

Mara: I would prepare for weeks whenever I had an appointment just to end up cancelling it cause it was just too much. When I did go I'd rehearse everything I wanted to say over and over just hoping I'd be able to talk. The first time I actually went I did say most of the stuff I wanted to but then he said "we'll you're taking to me aren't you", and it's like, oh.. well.. what do you say to that..?

As Christon, et al., (2012) demonstrated, overcoming SM in one context may not result in overcoming SM in others. As Mara describes, it was only the result of extensive preparation which allowed her to speak at all, yet doing so served only to instigate further misunderstandings. Such a dismissal may be immensely destructive and harmful for any individual. For those suffering from a difficulty such as SM, which inherently causes a deeply felt sense of isolation from others, the possibility of detrimental consequences arising from such a dismissal may be further increased. Individuals may be dissuaded from seeking help in the future, or worse. Fortunately this was not the final time Mara sought help.

In a study by Schwartz, et al., (2006) concerning the diagnosis of 33 children with SM it was found that 23 of the children never received an accurate diagnosis from their primary care physicians and were not referred to appropriate services. Despite this the children's symptoms were described as being readily apparent. A number of factors may contribute to this failure, including the general rarity of SM and the unfamiliarity of health practitioners with the difficulty. This may be an issue which is exacerbated for adults and adolescents with SM as the difficulty is often portrayed as a childhood disorder. Furthermore the inherent communication issues sufferers face may also contribute to the difficulties encountered in facilitating understandings between health practitioners and sufferers themselves. The effects of misunderstandings may be highly deleterious, further engendering a sense of hopelessness for sufferers and ultimately prolonging their suffering.

For some, the task of seeking help was rendered almost insurmountable by the pain which arose from facing the prospect that one cannot overcome one's difficulties alone, as Sam described:

Sam: It's hard because it makes you feel so pathetic, I could write it down or I could have asked my sister or someone to help but then that makes you feel like you can't do anything. I guess that's true... but you sort of don't want to know it or face it so you just manage and get by. Till you just can't keep going.

Similar to Mark's experience, Sam's difficulties arise from the notion that one is supposed to behave in a certain way. In Sam's experience this is felt in response to seeking help alone and speaking about his difficulties. The alternatives, of asking for help or communicating through text would serve to diminish Sam's self-esteem by further highlighting his apparent failures.

The process of seeking help may often cause individuals to confront the painful reality of one's predicament. For some it may be experienced as an admission of failure which itself may result in lowered self-esteem, causing a further sense of powerlessness. For sufferers of SM these difficulties are accompanied by the practical problems encountered when trying to communicate with others and strategies which are employed to overcome the inherent difficulties speaking may similarly be felt as admissions of failure. Even if these fears and difficulties can be overcome there remains the potential for misunderstandings to occur and for any efforts made to appear futile. These data may go some way to explaining the question posed by Krynski (2003) of why adult sufferers of SM may avoid seeking treatment. It may be that for some, these obstacles seem insurmountable and are avoided due to the painful experiences and realisations which may result, and further, that even if these obstacles were overcome then there would be no guarantee of successfully finding help.

#### 4.3.3 The Influence of Diagnoses

In several participant accounts the point of diagnosis was a significant event which provided individuals with a sense of relief. Within participant narratives diagnosis marked a transition between a period of uncertainty, fear and a sense of

hopelessness and a new orientation towards recovery as individuals were emboldened by the knowledge that they were not alone in their difficulties. As Mark described:

Mark: Knowing that someone has figured out what was wrong I think was important. After my therapist mentioned it I looked it up and things that other people had said. It's like yeah this is it, they sounded just like me. For so long I didn't even know I had anything that had a real name or that other people had the same thing and if doctors can't even tell you what's wrong then you really don't expect them to be able to help a lot.

As the previous theme concerning isolation discussed, a sense of alienation from the world and from others was a common feeling and a difficulty which pervaded multiple areas of participants' lives. To a degree this sense of isolation may be lessened by the knowledge that others have suffered from similar experiences. Online communities, or merely reading about others experiences, may serve an important cathartic function by instilling a sense of hope and optimism from the knowledge that one is not suffering alone. Mark also describes the perceived impossibility of help without having received a diagnosis, as, if no one understands the problem, then it would follow that no one would have knowledge of the solution. A similar experience was described by May:

May: Finding out what I had was SM, it was like finally you know, like I'm not just broken and won't ever get better. Knowing that it's something other people have and can get better from it's like, you finally feel well then maybe I can get better too. It lets you know it's possible at least.

Knowing that she was suffering from a difficulty which others had recovered from created a sense of possibility for May. This potentiality for improvement also appeared to alter May's own conceptualisation of her suffering, as May no longer viewed herself as a person who was "broken" or irreparable.

Receiving a diagnosis for some however was a difficult process. Mara had previously described some of the difficulties which visiting her GP had entailed. It was ultimately her own resourcefulness and research which led her to being diagnosed with SM:

Mara: I read about SM online when I was trying to work out what was wrong with me. The last time I went to the doctors before getting counselling I actually took in some information I'd printed out and handed that to them. I felt weird doing that because they're supposed to know these things, I'm not supposed to tell them.

The potential catharsis of diagnosis appears somewhat lacking in Mara's experience as although she is forging forwards and searching for answers herself, doing this alone is felt as abnormal in some instances. It may be that the notion of a knowledgeable other, a therapist or doctor, facilitates a sense of potentiality and provide reassurance that one isn't alone on their path to recovery.

A further interesting issue regarding diagnosis was also raised by Rose surrounding the label of Selective mutism:

Rose: It was good to know that what I had had a name, but selective mutism is just a really bad description of it. I've told people in the past that I had selective mutism and how that was why I couldn't always talk to them and more than once people have said "well just stop being so selective then" and then you have to try and explain that you can't control it. I always thought it should be called involuntary mutism or something because that's how it feels.

While some relief is again described as a result of the knowledge that one is suffering from a recognised difficulty the naming of selective mutism does little to reflect the embodied experience of the difficulty for Rose, presenting further difficulties. Elective mutism was renamed Selective mutism after debates concerning the deleterious effects of positioning SM as a chosen behaviour, with the diagnostic criteria being revised from describing a 'refusal' to describing a 'failure' to speak and being renamed as Selective mutism. While this may be a slight improvement, the term 'selective' implies that there is a selector and hence a degree of choice. Thus the label SM itself does not reflect the fact that this is not a conscious process, requiring further clarification.

One final topic regarding diagnosis illustrates the result of a lack of diagnosis, or misdiagnosis. Mark described his experiences of having received treatment for autism during his youth:

Mark: When I was about 13 or 14 I was sent to a sort of group therapy place. At that time they hadn't said I had SM, they didn't really say it was anything but all the other children there had types of autism. I didn't fit in there at all, obviously I couldn't say anything though. I think people assume that if you can't talk then you can't think properly either, not that kids with autism can't think properly but you know, it's more unchangeable sort of I think? Even with SM I could talk to my family so clearly I wasn't limited in that sense, if you know what I mean. That really put me off trying to get help for a long time because people just didn't understand.

While Mark was unsure of whether he was ever given a diagnosis during his youth, he experienced the resulting intervention as largely unhelpful. Mark also described feeling as if his difficulty speaking influenced the perceptions of others and that they may have underestimated his abilities. Speech may often be used as a simple indicator of cognitive ability, as children develop they are expected to move from being unable to speak to speaking fluently and with an ever increasing vocabulary. It is then perhaps unsurprising that some individuals may erroneously judge those who appear unable to speak to be unable to do so due to inherent learning difficulties. The lack of understanding which Mark felt regarding his difficulties also made seeking help seem a futile endeavour, and it would be almost 20 years later until Mark felt it would be worthwhile to seek help again.

Accurate diagnoses may be critical in providing individuals with access to relevant services and furthermore may enable individuals to gain a powerful sense of catharsis from the knowledge that they are not suffering in isolation. However diagnosis may result in other issues, such as leading to further stigmatization and potentially greater misunderstandings, as in May's experience. As Yalom (2002) has argued diagnosis may inexorably limit understanding. Selective inattention may arise as healthcare professionals ignore factors which do not fit with their diagnosis, while simultaneously over attending to those which do.

This issue regarding diagnosis was one which I had personally experienced as, at around the age of 12, I attended sessions with a counsellor who believed that I was suffering from Asperger's syndrome. Indeed many characteristics are shared by Asperger's syndrome and selective mutism; there may be a failure to develop friendships and individuals may appear withdrawn or awkward. There are also many ways in which these two difficulties are dissimilar, those similarities which do exist are of course accounted for by the silence of SM and the resulting social isolation. What has remained vivid in my mind however were the ways in which innocuous behaviours were taken as evidence for a certain diagnosis: In one instance my mother had spoken with my counsellor, who had asked about any repetitive behaviours I had demonstrated as a child. It emerged that as a child I had played with toy trains and would often arrange them in lines or neat semi-circles. This was taken as evidence of repetitive behaviours and further solidified my counsellor's belief that these were signs of autism. Had anyone asked me, they would have found out that this was not in fact a manifestation of obsessive or repetitive behaviour, but that I imagined, when I was not playing with them, that my toy trains were asleep in an imaginary train shed, hence their arrangement.

## **4.4 Experiences of Therapy**

This theme explores participant experience of therapy. All participants had received counselling or therapy for SM, which for most participants contained elements of cognitive behavioural therapy. Both the relationship between participants and therapists as documented within participant narratives and the experiences of participants regarding the therapies they received are explored.

### **4.4.1 The Therapeutic Relationship and Silence**

One common theme among participants concerned the nature of communication between themselves and their therapists and counsellors. For some participants the atmosphere of therapy was felt to be an impediment to establishing an honest and open dialogue for a number of reasons.

For Sarah, a lack of communication arose due to several factors. Firstly from her concern for her therapist and the perceived possibility that, should she disclose the extent of her difficulties, her therapist may have abandoned her. Secondly, Sarah



felt unable to discuss certain issues in order to avoid appearing ungrateful, despite feeling that some aspects of therapy were not entirely helpful.

Sarah: A lot of it [therapy] seemed to be getting booklets about how to breath properly or relaxation which I don't think had anything to do with my problems really. But you just take it and nod and smile. And I know that sounds kind of ungrateful because they're trying to help and I don't know what to do either. It's sort of like... I felt bad for my therapist, so maybe in a way I made my problems seem less severe, in case they got fed up with me.

Sarah continued to describe how both the therapy situation itself and her difficulties speaking made it difficult to open up during therapy. Though Sarah did eventually begin talking to her therapist she stated that she never felt comfortable enough to discuss the true extent of her difficulties.

Mara described how the act of writing responses caused her conversations with her therapist to become stilted. Mara presents an image of therapy as an emotionless endeavour as she provided what she believed was expected of her:

Mara: It wasn't like I imagined, I thought it would be all about talking (or writing) through problems - first getting to the stage where I could talk even. It was more like he would ask a question, like how do you feel in this situation, and I'd write down an answer just to give him something and he'd talk about that for a bit. There would always be some kind of task to do too, like one week it was to go up to a stranger at the bus stop and say hello but I didn't do it, because who does that?

A study by Ayers et al., (2012) exploring therapist and patient perspectives on cognitive-behavioural therapy found that while homework compliance was viewed as important factor by therapists, actual compliance by patients was poor. Data suggest that for short term therapies, such as CBT, homework compliance may be closely linked to treatment outcome (LeBeau, et al. 2013). Several methods for improving compliance have been suggested such as motivational interviewing (Aviram & Westra, 2011), using online materials to document homework compliance and by contacting patients directly to remind them to do

their homework (LeBeau, et al. 2013). None of the proposed suggestions however venture to engage the patient in a personalised therapy or to make relevant the patient's own perspective regarding the usefulness of their assigned homework. Instead the proposals tend to deny the value of patients' experienced worlds by failing to consider why individuals feel unable or unwilling to comply, inherently stifling the ability of the therapist to facilitate and sustain an empathetic and genuine relationship with the patient. As in Mara's experience, the therapist may begin to be viewed as an unhelpful figure who assigns equally unhelpful tasks. As a result therapy may break down into a cycle of appeasement as the patient attempts to avoid the negative consequences of their actions and uphold whatever meagre and inauthentic relationship that has been established, which may represent the only hope sufferers feel they have to overcome SM:

Mara: It's sort of like if you don't do what they say then you're not trying hard enough, and you feel as if they're blaming you, it wasn't helping me get over the things that were stopping me talking it was just saying, go here and talk. If I could do that then it wouldn't be a problem would it!

Similarly to Mara, Sam described how the artificiality of the patient/therapist relationship caused him to feel as if his difficulties were not being taken seriously:

Sam: They don't really care do they, it's just their job. I didn't feel like I could talk to them even after getting to the point where I could say things. Like every time I went they'd give me a form to fill in, it had stupid questions like if I was hearing voices and things and they knew that wasn't why I was there, but it also had questions about if I'd thought about suicide a lot of the time I had but it's like, shouldn't they be asking about that? and not just ticking a box on a form every week and they probably didn't even look at it.

Sam's experience of an unsympathetic therapy is summed up by the notion of a life or death issue being reduced to paperwork. The mechanical artificiality of this aspect in particular seemed to reinforce Sam's view of therapy and the therapist as being unhelpful and uncaring.

The healing role of the therapeutic alliance within therapy has been consistently documented (Everall & Paulson, 2002; Arnd-Caddigan, 2011), as have the deleterious effects of inadequate therapeutic relationships (Orlinsky, et al., 2004). However the need for an authentic and collaborative bond between therapist and patient is often portrayed as an extraneous variable which is not necessarily integral to the overall outcome of therapy. Raue and Goldfried (1994, p.135) described the therapeutic alliance within CBT as analogous to anaesthesia during surgery: As a helpful tool which once established becomes largely irrelevant to the therapist. Authenticity however may not be a state which is permanently achieved but a mutual and ongoing process which must be sustained, the former view may be highly manipulative, leading to inherent power imbalances within the therapy dynamic. Foucault's analysis of knowledge and power (1980) suggests that the task of building such a therapeutic alliance would be reliant on both therapist and patient being actively engaged in the process of 'unpacking' narrative stories (Brown, 2007). Both patient and therapist possess co-existing positions of "knowing" which are inherently interpretative and when recognized by both parties would serve to equalise the balance of power and facilitate authentic dialogue. This important balance of power was largely absent from the accounts of participants as they spoke of therapy, and a discourse of passivity pervaded their experiences. Participants repeatedly described the way in which tasks were set and expected to be completed regardless of the value participants placed upon them.

If therapy is felt to consist of little more than a predetermined series of scheduled tasks then it follows that any emerging alliance between therapist and patient will be similarly inauthentic, mirroring the artificiality of this imbalanced relationship. This presents a further issue to the therapeutic endeavour itself which seeks to engender increased agency and power within the patient. Though the power dynamics of the therapy situation may be unavoidably one sided this may be increased by therapies which are perceived by patients to neglect their voices. SM may further contribute to this by limiting the potential for an emerging dialogue between patient and therapist, meaning that a resilient and authentic therapeutic alliance is of yet greater importance for these individuals.

In contrast to the perspective of therapy as a series of tasks there is the view of therapy as a collaborative enterprise, with both patient and therapist working to overcome the barriers of SM. Rose described her experience of such a therapeutic relationship:

Rose: It took a long time to just be able to talk to my therapist but they really helped a lot just saying things that were encouraging but not too pushy. At first I'd write down most of what I wanted to say, sometimes I'd answer some questions until we sort of just built it up from there. It's like we were chipping away at this huge wall and my voice was on the other side.

Rose describes an empathetic relationship between herself and her therapist, with the illustrative metaphor of breaking down a wall being prefaced with an inclusive "we". Yalom (2002) has described the therapeutic alliance as being one between 'fellow travellers', which mirrors Foucault's concept of equal positions of 'knowing' which must be recognised to facilitate authentic interaction. A sense of inclusion, of facing obstacles together, and perhaps the sense of togetherness itself, may facilitate recovery from SM and the concomitant loneliness and isolation which sufferers face.

#### 4.4.2 Thinking a Way Out

A core assumption of CBT is that faulty cognitions play a large part in the development of 'maladaptive' patterns of behaviour and neurosis (Clark, 1995; Beck, et al, 2001). A substantial portion of this typically short-duration therapy is dedicated to the process of cognitive restructuring, identifying 'negative' thought patterns and core beliefs, understanding how these may sustain a certain cycle of behaviour and learning to challenge those thought patterns with more healthy ways of thinking. This was one issue participants spoke about at length when recounting their experiences of CBT. For some individuals this aspect of therapy was not particularly helpful, as Sam recounts:

Sam: She [Sam's therapist] would start with asking me to identify my negative thoughts but all my thoughts were negative. No friends, no job, no education, no future, that's how it is when you can't speak to people, I

know that I sometimes think I'm worthless or whatever because of that which is why I want to work on changing those things. But it was like ok, let's not look at those things just how I feel about them. Of course I felt bad about them, I know they're there I know they're not nice thoughts but I don't think they're wrong thoughts.

Again Sam identifies the main issues which affect his life with SM; his lack of friends, education and his fears concerning the future. Sam's experience suggests that the thoughts and feelings which were being dealt with during therapy were not the core issues which Sam believed should be addressed, but were a result of suffering from SM. Sam recalled his experience in more depth regarding the issue of loneliness:

Sam: Like being lonely, we'd look at how that made me feel and what my thoughts were and then she'd write them down on a board in a circle showing how the thoughts led to feelings which led to behaviours and back around. But it's like I'm not alone because I feel bad I'm alone because I can't talk to people, my thought there is that I really would like to talk to people, but can't, I don't think anything, I just feel that I can't, I have no one to talk to even if I could though. But having no one to talk to apparently was not a problem and I should have just been thinking better till I felt better.

Sam expressed a great deal of frustration when speaking about this topic. Sam later explained that because of SM he was unable to properly express how he actually felt about these issues to his therapist and wondered if that would have made any difference. The purpose of the cognitive component of therapy, as defined by Clark (1995) is to identify maladaptive cognitions and to subject them to 'logical analysis and hypothesis-testing' to realign patient's manners of thinking with reality. This view however may serve to devalue or dismiss the impact of factors beyond those beliefs which may influence an individual's way of being, such as genetic or biological factors, as well as life circumstances and other factors which may play a role in individual's difficulties, and may be viewed by sufferers themselves as being of greater importance.

Cognitive therapy distinguishes between facts relating to an external world which are unchanging, and values which are within the mind and alterable and it is this ontological fact/value split which may result in a devaluing of individual's inner worlds. It is also inherently difficult to disentangle facts from values in certain instances. As with Sam's example of loneliness: 'I am alone' is a fact whereas 'I am lonely' is viewed as a value judgement, yet the two are evidently related and there exists no evidence that such a value judgement is in any way faulty. As Teasdale (1997) has argued implicational beliefs such as these which reflect a felt experience may not possess an assessable truth value. Teasdale argues that rather than attempting to expose semantic flaws in an individual's sense of understanding it would be more beneficial to focus on changing one's actual way of being. This seems to be echoed by Sam's acerbic remark that not having anyone to speak to was apparently not considered relevant to his experience of loneliness during therapy.

Mara also experienced difficulties attempting to identify automatic thoughts and test those thoughts against other ways of thinking, though unlike Sam her experience is characterised by a sense of failure rather than frustration:

Mara: I remember one session where I was supposed to have gone away and tried looking at my thoughts and thinking different thoughts whenever I started thinking negatively. I found that really hard to do because it felt like I was just inventing thoughts to explain why I felt sad which just gives you more reasons to feel sad. I tried explaining it to my therapist which is not easy to do when you can hardly say anything and he just said I had to try harder. I still don't know what I was supposed to DO to try harder. I went home after that session and just burst into tears it made me feel useless like I can't even think right.

Mara describes her confusion at being asked to subject her thoughts to a logical analysis when being provided with little guidance on how to actually do so. Her failure to live up to the expectations of her therapist were also described as greatly upsetting. In Mara's account her interaction during therapy is not described as a collaborative process with her therapist, but as a series of instructions which she is expected to follow.

The logico-deductive process of challenging 'maladaptive' representations is poorly explained within CBT literature. One is expected to notice one's own pattern of thoughts and core beliefs, challenge them, and ultimately alter them. However no instruction is provided within the literature detailing this as a working process which can be mentally undertaken. Both Sam and Mara's accounts of their experiences with cognitive therapy convey a sense of futility at attempting to rethink their ways of thinking. Reflecting upon these transcripts I recalled the following remark by the philosopher Alan Watts (1960), which seemed to capture the essence of these individuals' difficulties:

"It's like desiring not to desire, or loving out of a sense of duty, trying to be spontaneous because you ought to be. See, all that is nonsense, lifting yourself up by your own bootstraps."

A thought experiment by Robert Nozick (1990) similarly explores this idea through the experiences of a Holocaust victim who is able to distract himself from the horrors of reality by focusing upon pleasant memories of music. If this were an individual's permanent reaction in such a situation surely it would be bizarre? It would be a pleasing alternative but a delusional state and a denial of the reality of one's situation. Certain therapeutic paradigms may be excluding the reality of an individual's suffering by situating suffering as a judgement value rather than as the existing reality of an individual's experiences. CBT presupposes that individuals are responsible for constituting their own interpretative realities yet, as the participants in this study described, it may be that the crucial step of facilitating a sense of willing and hope, which may have enabled individuals to alter their way of being, was missing. As Yalom (1980) has argued, assuming responsibility for one's own way of being is essential if change is to take place. If, as in the two accounts by Sam and Mara, individuals feel powerless, either due to life circumstances or their lack of ability to combat negative thoughts then despite which orientation is taken, those obstacles may first have to be removed if change is to be seen as possible.

In contrast to the difficulties which other participants described, Mark provided a more positive account of his experience with CBT, though he too describes a

disconnect between the embodied experience of SM and the process of reflecting upon his thoughts:

Mark: Learning to step away from my way of thinking helped in some ways, like with depressed thoughts so I could sort of distance myself from those thoughts and not dwell on them [...] It isn't as useful in dealing with SM, because that isn't really a thought thing, you know, I wouldn't think I can't talk and that makes me not speak, it's more automatic and it doesn't matter what I'm thinking it always requires a lot of effort to try and say anything. Hopefully that'll change with just doing it more and eventually it'll get easier.

The embodied experience of SM concerning the lack of control and the felt inability to speak are factors which are rarely discussed within the literature. Effective therapies may need to find ways to tackle these issues, as adults who have suffered from SM for extended periods may be less receptive to treatments which have shown success with young children. Adult sufferers may face barriers to recovery which have built up over the course of their lives, from practical issues, such as having few opportunities to socialise, to issues relating to lowered self-esteem and the embodied feeling of being unable to speak. If these experiences are not understood by healthcare practitioners, and as they may be unlikely to be easily communicated by sufferers of SM, there is a danger that core aspects of this difficulty are being overlooked, potentially to the detriment of sufferers.

## **4.5 Master theme 5: Towards the Future**

This final theme explores participant perspectives of the future, and the phenomenology of despair and hope which participants experienced. In several cases the strands of meaning and hope which sustained sufferers revolved around their personal connections with family and friends. This final bulwark against despair provided individuals with the strength to go on when hope faded and fear and uncertainty took its place.



Mara described how the events of her past led to feeling as if there would be few future opportunities for change, as all her attempts thus far had been felt to be ineffective:

Mara: It's hard thinking about the future, I think you need to have something there to look forward to, but there isn't anything. I've tried a lot of things on my own, seen counsellors, been on anti-depressants and all that. Maybe that makes it worse because it feels like now there's even less hope of anything changing.

Mara described how the events of her life led to, and provide evidence for, her realisation that nothing and no one could help. Conveyed is a sense of running out of options and of increasingly decreasing possibilities in which change might occur. A similar sense of dejection was described by Sam:

Sam: Well, sometimes it feels like I've tried everything I can and I don't know how to get better or what there is left to try more than I'm trying now.

Later Sam spoke about what remained in his life beyond this hopeless sense of futility:

Sam: I hate a lot of things about my life and honestly if I was completely alone and like this I don't think I'd be here, but I still have my parents and my sister. I think of it like there's all this sadness in me and my life but if I wasn't here then all that would go to them, so why would I do that. So as long as I have people who care that I'm here then I'll be here for them no matter what.

Within previous themes regarding SM and isolation we explored how the dehumanising effects of loneliness could result in a sense of separateness from the world and those within it. Yalom (1980) argued that such a process was "inherently noxious" as life takes on an absurd meaninglessness if viewed from too great a distance. Here however we find its opposite, a humanising empathy and a meaning for life despite the difficulties arising from SM. Something of Frankl's (1965) technique of meaning finding through dereflection, a process of diverting one's gaze towards others in a search for meaning, seems apparent in

Sam's experience. Though Sam acutely feels a sense of futility and sadness in life he can spare others from a greater pain by continuing to live. Thus a life diminished by SM may still take on a powerful sense of meaning.

May found a similar powerful motivator through her interactions with other sufferers of SM:

May: One thing that really keeps me going is having met other people online with similar problems, some with SM too. I know there are going to be ups and downs and knowing that I have friends who will stick with me even when I don't want to stick with myself is probably the biggest help and knowing that I can be there for other people too and things don't always have to be so bad.

May had met a number of friends through online support forums and the process of being helped and providing help to others was described as a powerful motivating force.

Sarah also described how meaningful social interactions with friends and family helped her to cope, as well as describing a practical act which helped her to remain positive:

Sarah: I hope things will get better. Sometimes I have to remind myself of the things that have got better, I actually keep a list that I look at when I'm feeling really crap. I have my dad and a really good friend I met online who has SM too and there are times when I've said a few words, and that's something, it's a few more than nothing.

By dwelling upon things which had improved and the positive aspects of her life Sarah facilitated a sense of hopefulness which was otherwise lacking. Although several participants described the beneficial nature of social interactions which remained in their lives, this itself had the potential to provoke anxiety, as Rose described:

Rose: The future is kinda scary. I know I'm trying everything I can but I still worry sometimes that I'll never feel any better. I think everyone probably worries about the future a bit, about getting older and other

people getting older. I think maybe that's harder though if you have SM because if the people I talk to now end up not being here then that's kind of it.

Being the only defences against isolation Rose's interactions with friends and family took on further significance. The realisation that at some point the people Rose cared for may no longer be there, coupled with the possibility that Rose may never overcome SM created an anxiety provoking perspective of the future. As social relationships were closely entwined with forming meanings and in finding a purpose to continue through life then the loss of those relationships may be incredibly difficult for sufferers of SM.

Though there are many ways in which I feel that I have overcome SM there are a number of ways in which I feel that I have not. Like the other participants in this study there have been occasions when I could find little comfort in evaluating my own life, which at those darker times seemed to consist only of failures and lost opportunities. Like others, I found that holding onto those things which SM could not take from me kept the present bearable and the future hopeful.

## Chapter 5: Conclusion

This chapter will summarise the goals and the main findings of this research. Recommendations for future research will also be discussed alongside a reflection of the processes used in the present study

This research aimed to explore the lived experiences of adult sufferers of selective mutism in a way which would provide such individuals with a voice and a presence within the literature. Existing literature contained only sporadic mentions of adult sufferers. As a result little was known about the effects of SM during adulthood, what impact this difficulty might have on an individual's quality of life and the potential outcomes for those who sought help for SM as adults.

This research aimed to address these issues by conducting a qualitative investigation into the life-worlds of those who had experienced SM, exploring the perspectives of sufferers and the narratives that they constructed with the goal of furthering our understandings of selective mutism in adults. By engaging in a co-constructive hermeneutic process of understanding, as opposed to a researcher centric perspective, this research aimed to facilitate an understanding which moved beyond those which had thus far been developed from predominantly quantitative research methods.

The main areas explored by this research included the narrative journeys of participants throughout their adult lives, their experiences of seeking and receiving treatment for their difficulties and how these individuals constructed meaningful interpretations regarding those lived experiences.

Regarding the strengths and weaknesses of this research, I acknowledge that my own first-hand experience of SM has the potential to be both a strength and weakness of this research. However by including data from my own life experiences it is hoped that this may be seen to have strengthened this work and to have preserved its phenomenological validity. Including my own experiences within this research was at times a challenge itself. My confidence to share my own experiences was greatly facilitated by the candidness and openness of the other participants within this research.

The inclusion of participant input regarding the preliminary identification of themes is also considered a novel strength of this research, serving to promote the inclusion of participant voices as fully as possible and to ensure the grounding of findings within the data itself.

At times it was challenging to analyse and coherently formulate the emergent themes of this research due to the sheer amount of data provided by participants. Though this is an issue which may be intrinsic to any attempt to explore life experiences. Achieving focus in this sense was often difficult as there was always a choice between investigating further into one specific area of participant experiences or focusing upon the broader phenomenological essences of experience, each often at the cost of the other. While no phenomenological exploration can ever be comprehensive it is however hoped that this research has meaningfully captured something of the experience of SM.

## **5.1 Summary of Essential Themes**

The aim of phenomenological inquiry, as stated by Van Manen (1990) is to arrive at the essence of lived experience. This research has identified a number of essential themes regarding the phenomena of selective mutism through an exploration of the life narratives of those who have experienced this difficulty during adulthood. The ontological question of what it means to suffer from selective mutism for the individuals within this study was an experience shaped by isolation and a sense of deep regret towards a life lived trapped within silence. Further explored were the desires of participants to be understood and to connect meaningfully with others in their lives, a desire which had in various contexts and at various times been denied.

The embodied experience of SM for participants was one of loss. A loss of the spontaneity and effortlessness of every day speech and by extension a loss of the ability to present themselves to others as the individuals they felt themselves to be. The result was for some a sense of no longer being in control of their own voice, a sense that they had failed themselves, and for some a deeply felt sense of regret.

SM as a steadily worsening process was also explored throughout participant narratives. Existing literature has been divided between an explanation of SM as having a sudden onset triggered by traumatic experiences and of SM being a slowly reinforced learned behaviour. This research found that individuals attempted to find a meaningful origin for their difficulties but that this was followed by a steady progression, whereby silence moved beyond what might be expected to result from the initial events connected with onset to other multitudinous contexts. This made it increasingly difficult for individuals to find further meaning in understanding their difficulties. For instance a silence which may have been perceived to result from bullying at school might eventually grow to eclipse relationships with close friends and family.

The experience of long term isolation was also central to the experience of SM. As isolation begat further isolation individuals attempted to find meaning in these events. However overwhelmingly the rationalisations made by individuals were detrimental to their self-esteem as they attempted to answer the question of why they were alone. This powerful source of anxiety would for some lead to feeling as if re-integration within the world was impossible and created a sense of hopeless futility that coloured their experiences through life.

The themes which emerged as participants narratively conveyed their experiences of seeking help continued to expand upon these core phenomenological essences of SM. The task of initially seeking help was one in which individuals faced numerous practical issues to overcome the silence of SM, some of which served only to reinforce their feelings of abnormality. The findings of this study, though small in scale, support research which has suggested that primary care physicians may be missing or misdiagnosing SM (Schwartz, et al., 2006). Some individuals found that it took several years before their difficulties were eventually recognised, whilst others found that they themselves had to inform professionals about SM before help was forthcoming. The influence of diagnosis was described as a beneficial turning point in the narratives of several individuals, as this event challenged feelings that sufferers were alone. This was an important step in facilitating a sense of belonging for some as it compelled them to seek out online SM communities and others with shared experiences, abating loneliness and despair. Beyond this however the practical issues surrounding speaking to

healthcare professionals and the difficulties establishing authentic dialogues with therapists and counsellors meant that experiences of some participants once again became shaded by the despairing hopelessness which lay at the heart of SM. The sub theme 'Thinking a way out' explored the overwhelmingly negative recollections of participants towards the process of cognitive restructuring during CBT sessions. For many this endeavour was felt to deny the truth of their experiences, contributing yet further to a sense of distance which sufferers felt between themselves and the worlds of others.

Finally, in the theme 'Towards the future' an exploration of how the core essences of SM extend into imagined futures was undertaken. For many the few sources of hope and the comforts which remained were found in the islands of social interaction which survived SM and in which a sense of normality was felt. Often these important relationships were with parents, siblings and close friends. Yet these comforts were themselves often poignant reminders of those aspects of life which could so easily be taken by the silence of SM.

## **5.2 Unique Contribution to Knowledge**

This research has produced a rich ontological exploration of the life narratives of those who have experienced SM throughout their life. It is the only identified study to have employed IPA to identify, interpret and explore the essential phenomenological structures of lives affected by selective mutism.

This research is unique in its focus upon the experiences of adults affected by SM. This research has demonstrated that adult sufferers are willing and able to tell the rich and insightful stories of their lives, contributing valuably to our understanding of this uncommon difficulty, so long as efforts are made to communicate with sufferers in ways which are sensitive to the difficulties they face. I am privileged to have been given this opportunity to hear the stories of those who took part in this research.

The importance of phenomenological inquiry is not simply in asking what can be done with such knowledge, but in what that knowledge can do to us. It is hoped that this research will encourage a thoughtful reflection for readers regarding the themes identified and discussed within this research. Phenomenology does not

aim to achieve conclusive finalised data as experiences are recognised as unique and being by their very nature only partially communicable. This research is also a response to the continuing trend of research to focus upon data free of human qualities and which has become evidence-dominated whilst continually restricting that which constitutes evidence. This research encourages a return to an awareness and understanding of the unique human lives which are themselves the experiencers of the phenomena being studied. This research has demonstrated the human processes of sense making and meaning finding which apply to those experiencing and living with SM, challenging the notions of normality and abnormality which often dominate psychological research. Hopefully this research has succeeded in presenting those who took part in this research as fellow travellers, struggling as we all do with the human tragedies of existence, with regrets, with fears of what the future might hold, with the dehumanization of loneliness and with a wish to be accepted, understood and to be one's self.

Beyond the goal of phenomenological inquiry the present findings have also clarified further the relationship between anxiety and SM. This research has explored the way in which the embodied experience of being trapped within a silence which escapes meaning and reason contributes to a sense of isolation, creating and sustaining anxieties concerning one's loss of voice, loss of ability and loss of self-esteem. Furthermore this research is the first to explore phenomenologically the experiences of adults receiving CBT and counselling for SM. The findings raise a number of further questions and present opportunities for future areas of research.

### **5.3 Recommendations for Future Research**

This research suggests that there are a number of aspects regarding selective mutism which could be explored further. The following topics may provide additional insights into the experiences of adults with SM:

- A systematic comparison of treatment therapies used to help adults overcome the difficulties of SM. Within the literature review no significant research was found exploring effective therapies for adults. Many of the successful interventions documented within the literature have focused



only on children affected by SM. While the data gathered by this research cannot be used to support any conclusive statements regarding the benefit or detriment of any specific therapy it is clear that some individuals consider the treatments they have received to have been unhelpful. Future studies exploring the efficacy of any treatments for SM should include a qualitative component to understand the perspectives of the individuals being treated. The issues regarding communication, authenticity and the dynamics between the healthcare establishment and the patient themselves which have been identified within this research suggest that this may be best accomplished by impartial advocates of patients.

- Within this research all participants were under the age of 35. Future research may wish to focus on age groups beyond this. No identified research has explored the long term effects of SM. It would be interesting to return at a later time to this group of participants to understand how their experiences change over the course of their lives. At the conclusion of this research I was left wondering what would happen to these individuals whose lives had been so affected by SM.
- A number of further in-depth explorations may be undertaken regarding specific themes identified within the current research This may include the habituation and progression of SM throughout individuals lives and the role of regret and depression in seeking help.
- Exploring the experiences of family members and close friends of those with SM may also produce important data for understanding the dynamics of relationship which remain in spite of SM. Literature has primarily focused on the relationship between parents and their children with SM. Understanding the factors which facilitate communication, of which a number were discussed within this research, may be useful for understanding SM and developing effective support for sufferers.

## **5.4 Conclusion**

This research has explored the lived experiences of adults with SM, generating new insights from interpretative co-constructed themes which emerged from first-hand narrative accounts. It is hoped that readers will appreciate and be informed by the findings which this research has generated. This research will also hopefully promote an acknowledgement of adult sufferers and encourage further investigations into selective mutism beyond childhood.

Importantly this research has succeeded in providing a voice for those who often struggle to find one.

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# Appendix

## APPENDIX 1: Participant Information Sheet

IPA: Adults with Selective mutism and their experiences of health care and support services.

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### INFORMATION SHEET

You are being invited to take part in this study which aims to explore the experiences of adults with selective mutism, including their experiences of health care services.

Before you decide to take part it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with me if you wish. Please do not hesitate to ask if there is anything that is not clear or if you would like more information.

#### **What is the study about?**

The purpose of this study is to gain an understanding of the experiences of adults with SM. There is little research concerning the experiences of adults and there are several unanswered questions about the effectiveness of current treatments, the identification and diagnosis of adults who have SM and how people with SM are able to engage with health care services. I believe that one important way of exploring these issues is to engage with individuals who have firsthand experience of selective mutism to attempt to understand their perspectives on these issues, which can often be missed or overlooked, especially considering the difficulties individuals with SM can face.

#### **Do I have to take part?**

It is your decision whether or not you take part. If you decide to take part you will be asked to sign a consent form, and you will be free to withdraw at any time and without giving a reason.

#### **What will I need to do?**

If you agree to take part in the research you'll be asked to take part in two or three online interviews, using IM software of your choice. Each interview will take approximately one hour depending on how much time you have available, and these interviews can be arranged at various times depending on your availability to take part. In the interview topics relating to your experiences of SM can be discussed and you'll be given the opportunity to talk about the topics you feel are important, as well as describe your experiences of dealing with health care services.

#### **Will my identity be disclosed?**

All information disclosed within the interview will be kept confidential, except where legal obligations would necessitate disclosure by the researchers to appropriate personnel.

#### **What will happen to the information?**

All information collected from you during this research will be kept secure and any identifying material, such as names will be removed in order to ensure anonymity. It is possible that the research may, at some point, be published in a journal or report. However, should this happen, your anonymity will be ensured, although it may be necessary to use your words in the presentation of the findings and your permission for this is included in the consent form.

**Who can I contact for further information?**

If you require any further information about the research, please contact me at:

Name: Aaron Walker

E-mail: [u1052162@hud.ac.uk](mailto:u1052162@hud.ac.uk)

Thank You.

## APPENDIX 2: Participant Consent Form



### CONSENT FORM

#### Interpretative Phenomenological Analysis of Adult Experiences of Living with Selective Mutism

Thank you for considering being interviewed as part of my research study. Please answer the following statements concerning the collection and use of any gathered research data. The intent of these questions is to make sure that you understand the purposes of this study and are willing to take part.

I have been fully informed of the nature and aims of this research ..... ☐

I consent to taking part in it ..... ☐

I understand that I have the right to withdraw from the research at any time without giving any reason ..... ☐

I give permission for my words to be quoted (by use of pseudonym) ..... ☐

I understand that the information collected will be kept in secure conditions ..... ☐

for a period of five years at the University of Huddersfield..... ☐

I understand that no person other than the researcher/s and facilitator/s will have access to

the information provided..... ☐

I understand that my identity will be protected by the use of pseudonym in the report and that information that could lead to my being identified will be included in any report ..... ☐

If you are satisfied that you understand the information and are happy to take part in this project please put a tick in the box aligned to each sentence and print and sign below.

Signature of Participant:  _____  Print:  _____  Date:  _____	Signature of Researcher:  _____  Print:  _____  Date:  _____
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### APPENDIX 3: Participant Debriefing Sheet

#### Interpretative Phenomenological Analysis of Adult Experiences of Living with Selective Mutism

Thank you very much for taking the time to participate in this study, the purpose of which was to gain an understanding of Selective Mutism from those who are experiencing it and to explore the issues and challenges they face in the course of their lives. Your input may lead better understanding of the condition which could have implications for, and inform future research on, topics such as diagnosis, treatments and interventions.

I would also like to remind you that all information you provided will be anonymised, however if for any reason you would like to withdraw from the study (up to the point of finalisation) you have the right to do so and any data that you provided will be destroyed.

If you have any complaints, questions or concerns regarding the study or your participation in it, or wish to see a summary of the research (or the dissertation itself when available) please do not hesitate to contact me or my research supervisor at:

My Email: [u1052162@unimail.hud.ac.uk](mailto:u1052162@unimail.hud.ac.uk)

Thank you again for your participation in this study.

Aaron Walker

Preliminary Themes & Stages of Narrative	The development of emergent Themes	Emergent Themes	Participant Input	Grouping of Themes	Final Themes Sub-Themes
The onset of SM	Subsumption - themes of loss grouped, potentially under super ordinate status. Loss concerned so many aspects of sufferers experiences was difficult to find a way of representing them all under a single theme.	Lost voices	Mara suggested that lost voices be changed to trapped voices, as they are "lost, but not gone forever".	Lost voices became divided into two distinct sub-themes: Trapped voices exploring the emergent theme of the embodied sensation of SM, while Habituation explored narratives and sense making regarding the progression of SM throughout participants lives as a process of loss. Lost hope explores the emotional component - abstraction , grouped again under theme of loss.	<b>SM as Loss</b>  Trapped Voices The Habituation of Silence Lost Hope
Losing a voice		Lost hope			
Losing confidence		Regret and lost lives	Mara, Sam and Sarah felt that isolation was central in every aspect of their lives, as a result this theme was given super ordinate status. And separated from themes of loss.	The function of these themes was to explore as fully as possible the aspects of being alone through life and the search for meaning - presented together, beneath a super ordinate theme of isolation, they capture the essence of what felt like a call for help - following the narratives of participants into Journeys while also conveying the negative themes of despair and desperation which run throughout the narratives.	<b>SM &amp; Isolation</b>  Being Alone Falling out of the world
Losing friends		Isolation			
Losing self-esteem	Numeration - most common themes across participants were isolation and depression - embodiment of SM was same across all participants	Separateness from the world	Some participants reflected that they did not want to seem ungrateful to friends and family who had stood by them and attempted to make them feel less alone. After discussing these issues further I decided to move aspects of the emergent themes of isolation into Towards the Future.	As participants were especially concerned with their treatment during therapy it was decided to place themes relating to therapy within an overarching subtheme - within it an exploration of the narrative of silence in relation to interactions with the therapist and the sense of futility and hopelessness - continued throughout each master theme - represented here in thinking a way out.	<b>Journeys Towards Recovery</b>  Regret & Resolve Seeking Help The Influence of Diagnosis
Regret		<b>Narratives of cause</b>			
Missing out on life	A number of 'critical events' were noted as emerging from the narratives - commonly these concerned seeking help, and participant's progression through therapy.	Death - narrative events	After discussion the narrative emergent themes it was decided to organise them in a way which would capture the cadence of participant experiences. Moving from the depression of an unlived life to the task of seeking help & the hope instilled from diagnosis, before a return to despair. (polarization)	Kept the narrative structures intact, but divided themes further - experiences of therapy were important to several participants.	<b>Experiences of Therapy</b>  The Therapeutic Relationship Thinking a Way Out
Isolation		Bullying - narrative events			
Depression	Chose to keep the temporal narrative intact - emergent themes took on the qualities of a journey to capture the actual journeys of participant lives.	<b>Journeys through therapy</b>	Experiences of therapy captured the sense of anger and sadness participants felt regarding their experiences of therapy.	After the previous themes, moving through hopelessness, despondence, regret, resolve, hope and, sadly for most participants a return to a resignation of despair, tinged with anger over feeling regarding therapy, I wanted this theme to capture the kindness, hope and powerful empathy which participants had demonstrated. I decided to subsume despair within hope, leaving towards the future as a single theme	<b>Towards the future</b>
Making sense of loneliness		(Not) talking therapies?			
Finding ways to cope	Diagnosis acting as a central turning point between despair-hope-despair.	<b>Orientations towards the future</b>			
Seeking normality		Hope			
Seeking help	Participant narratives ended, unanimously, by looking into the future, speculating at what may happen - a constant balancing act between hope driving participants forward and despair threatening to overtake them - kept as functional themes.	Despair			
Transformation of diagnosis					
Failed recovery					
Hope for the future					
Despair in the future					



## **APPENDIX 5: Example Excerpts from Interview Session III**

(i) Interview III with Mara - Section on the topic of loneliness:

Aaron: In reading through our last two conversations it seemed as if there was a real sense of feeling separate from world, up until the point where you found out you had SM, would you say that sounded right?

Mara: Yeah, because well I know it sounds silly but it's as if your whole world is just you, in your head in a little bubble.

Mara: I was thinking about it a lot and its like you don't have any of the everyday normal stuff that people have so it's like everything goes on around you and you're just stuck. I mean what can you do there's no way to get out of being alone

Aaron: It sounds like it must have been very frustrating at times.

Aaron: So it played quite a big role in your day-to-day life then?

Mara: I still does really.

Mara: I mean I don't want it to sound like I don't care about my mother being here to talk to she's the only reason I been able to keep going and she's just the best thing in my life.

Aaron: I understand, it's something that a few other participants mentioned, that they could only talk to their parents and even though that was very important to them there was still a lot missing in terms of relationships with friends or colleagues.

Aaron: You mentioned the 'every day normal stuff' that you feel like you don't do, do you feel that it's when you compare your life to other people's that you seem to feel that sense of separateness more?

Mara: You can't help it really I think everyone compares their life to other people and with sm you think well I can't have any of that stuff, so yeah..

Aaron: Are there any things in that sense that you feel you're particularly missing out on when you compare your life to other people's lives?

Mara: Everything, haha

Mara: it all just sucks because I really want to do things with other people you know, I want to have friends and go places and have people to talk to and all that

Mara: but who wants to be friends with someone who can't talk to them? how would they end up being friends anyway it'd be like making friends with like a tree or something

Aaron: So you're saying you're like a tree? :P

Mara: haha in not being able to make friends then yep I'm a tree :)

Aaron: So, there seems to be two parts to this, on the one hand there's the fact that you're alone and that's very hard to cope with and on the other there's the sense that you wouldn't be able to fit in with other people anyway?

Mara: Yeah, so it just feels impossible..

(ii) Interview III with Sam - Section on the topic of therapy:

Aaron: In the last interview when you were talking about your experiences with counselling it seemed like one of the big issues was that it didn't feel for you that your counsellors were really listening to the things you had to say?

Sam: I don't think they cared tbh

Aaron: Do you think SM played a role in that, in influencing the relationship between you and your counsellors?

Sam: Maybe if anything I think I noticed it more

Sam: cus obviously I didnt say a lot

Sam: but when I did say something then it was like they just didnt care

Sam: if it was something I wanted to say for weeks and for once did

Sam: maybe they'd say oh well done for saying that, like I was an idiot or something

Sam: but they wouldn't listen to the thing I actually said

Aaron: So you feel like they listened to the act of you speaking, but not to the content of what you actually had to say?

Sam: yeah

Sam: it felt like they just wanted me to listen and do the stuff they said

Aaron: What effect do you think those experiences had? I remember you saying that you wouldn't try counselling again because of your previous experiences.

Sam: yeah

Sam: I think thats the thing I learnt from it, they're just paid to sit there and listen to you

Sam: I have family who listen because they care and want to help because they care

Sam: and to be honest they're more helpful because they don't just see me for 45 minutes every week

Sam: one thing my counsellor said in one of the first sessions was that there wasn't a magic wand they could wave just to make me talk

Sam: when you think, it took all these years for my SM to get this bad, wouldn't it be the same to get better?

Aaron: So you think the journey and the experiences you've been through so far would have to find it's opposite in a journey back towards eventually overcoming SM?

Sam: exactly, if I've had SM for ten years then won't it take a long time to get better, not like the 20 hours they give you for counselling

Sam: I mean I'm definitely making steps to getting better and I'm trying to make things better and trying to talk in every situation I can, even though there aren't many

Aaron: It sounds like it's been really difficult, I suppose therapy helped in a rather odd way there by giving you a kind of confidence to make it better on your own then?

Sam: yeah, it's like, I've got by so far, so I can keep going

(iii) Interview III with Sarah - Section on the topic of embodied SM

Aaron: Another thing that seemed important in your last interview was the way you felt that SM was stopping you from saying the things you wanted to say?

Sarah: Yeah it's as if there's literally something blocking you from talking

Aaron: So from that there's no real way to, in a sense, represent yourself to others?

Sarah: yeah that's really it, I remember, I think, it could have been a doctor or one of the counsellors I used to have, said something like 'it could be a personality disorder and there's nothing we can do about that '.

Sarah: and you just think, well I know what my own personality is like and it's not being unable to talk.

Sarah: How would that make any sense, if I enjoyed not talking why would be there trying to get help so that I could talk?

Aaron: So, it sounds like what you're really trying to find is a way to express who you are, which has in a way become lost behind SM?

Sarah: That's it, like I said the other day, I know I can talk and I can be me because when I'm with my dad I can still talk and feel like I'm ok and before I had SM I was just like other kids. So I know for a fact that it isn't something wrong with my personality.