Selective Mutism in Adults: An exploratory study

PS7112 Dissertation

(Psychology for conversion MSc)

C. Sutton

1221602@chester.ac.uk

Supervisor: Dr M. Tytherleigh

m.tytherleigh@chester.ac.uk

Department of Psychology

University of Chester

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1. Declaration

This work is original and has not been submitted

in relation to any other degree or qualification

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C. Sutton (1221602@chester.ac.uk)

2. Acknowledgements

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Sincerest of all thanks to all 83 adults who participated in this research. I hope that this dissertation, and any other research that may stem from it, do justice to your own experiences of - and thoughts and views on - Selective Mutism, which I have attempted to incorporate as inclusively and completely as I can.

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6. Abstract

Selective Mutism (SM) is generally perceived to be a condition of younger childhood and something that children tend to grow out of (Standart & Le Couteur, 2003). There is a lack of studies to show that SM in adolescence and adulthood exists. The aim of this study, therefore, was to explore, for the first time, the lived experiences of adult sufferers of SM from their own perspectives. An opportunity sample of 83 adults, who reported having SM when turning 18, participated in the study. A formal diagnosis of having SM in childhood was not required. Data were collected using online questionnaires. Additionally, adult sufferers of SM were invited to submit life stories. Both quantitative and qualitative analyses were carried out.

Amongst the findings, the results support previous research on children to show that the mean age of onset of SM was before 4 years old, with many participants conveying their belief that they had SM since birth. The negative effects of having SM peaked during adolescence for most. High levels of comorbidity with other anxiety and mood-related disorders were common in adulthood. As one of the largest studies to be carried out on SM, the results provide clear evidence that SM in adults does exist and is likely to be a worldwide phenomenon. They also provide some justification for the recent reclassification of SM as an anxiety disorder, though not specifically a social anxiety disorder, in the DSM V (APA, 2013).

7. Introduction

Selective Mutism (SM) is popularly perceived to be a condition of younger childhood and something that children tend to grow out of (Standart & Le Couteur, 2003), despite evidence that SM can continue into adolescence and adulthood (Remschmidt, Poller, Herpertz-Dahlmann, Henighausen, & Gutenbrunner, 2001). When SM does persist, however, SM is also considered chronic and resistant to change (Gray, Jordan, Ziegler, & Livingston, 2002). While the incidence of SM is said to reduce by adolescence (Manassis, et al., 2003), there appear to be no population studies to indicate how many adolescents or adults with SM exist. As, ostensibly, a 'rare' disorder, SM is not specifically included in large-scale epidemiological studies on mental health issues such as The Fundamental Facts (Mental Health Foundation, 2007).

Though evidence suggests that very early intervention with SM is most important regarding long-term outcome (Keen, Fonseca, & Wintgens, 2008) and suggests that early intervention restores a child's ability to function in challenging situations (Cline & Baldwin, 2004), the dearth of research in SM in adults is curious because long-term outcomes for SM are important in order to create guidelines for working with children and adolescents with SM (as asked for in Standart & Le Couteur, 2003; Storgaard & Thomsen, 2003) also.

Population studies indicate that SM has a diagnosis rate of approximately 1 in 555 children between ages 7-15 (Kopp & Gillberg, 1997). Anecdotally, SM is thought to be underdiagnosed however; and, additionally, SM is thought to exist in a larger number of adults than is currently assumed, particularly in light of the anecdotal evidence that SM is very often comorbid with Asperger Syndrome (AS). This current research intends to demonstrate that SM in adulthood is not rare, and to indicate that most adults with SM did not receive a diagnosis of SM in childhood.

This current research on SM in adults was also undertaken by an adult who still has SM from childhood. As such, SM still has clinical significance for many adults, contrary to the few long term studies that exist which point to its usual remission by young adulthood (e.g. Steinhausen, Wachter, Laimböck, & Winkler Metzke, 2006).

The aim of this study was to explore SM in adulthood and, in particular, to report the personal views of adults, on their own experiences, who either still have SM from childhood or recovered in adulthood. Also to explore how SM impacted on aspects of their lives in areas such as psychological / mental health, education, family life, and social functioning. Further aims of this research are to evaluate the new classification of SM as an anxiety disorder, though not specifically a social anxiety disorder, in the DSM V (APA, 2013); and to better inform education and mental health practice by evaluating the longer-term outcomes of SM, which have been researched here for the first time. A long-term study on SM is also intended to, potentially, demonstrate the implications (including long-term cost indications) of *not* investing in the treatment of SM in children, when it is most easily treatable; and *not* investing in the related training of clinicians (psychologists and psychiatrists.)

7.1. The history of Selective Mutism

SM has undergone major name changes over time, based upon changes of conceptualization: from Aphasia Voluntaria (Kußmaul, 1877); to Elective Mutism (Tramer, 1934; APA, 1980; APA, 1987); to Selective Mutism (APA, 1994; APA, 2000; APA, 2013).

Regarding conceptualization, it took more than 100 years for the involuntary nature of SM to be formally recognized via the epithet ‘selective’ (indicative of failure to speak in specific situations) compared to ‘elective’ (refusal to speak in almost all situations) or ‘voluntary’ (choosing not to speak). This last change of emphasis was largely due to The Selective Mutism Foundation (Selective Mutism Foundation, 2012). Note that Elective Mutism is still the preferred term for SM in ICD-10 (WHO, 2010).

Elective Mutism was first included in DSM III (APA, 1980). In the DSM IV-TR (APA, 2000) it was still listed as a “disorder usually *first* diagnosed in infancy, childhood, or adolescence.”

The principle change in the DSM V (APA, 2013) from the DSM IV-TR (APA, 2000) is that SM is now deemed an anxiety disorder, though not specifically a social anxiety disorder.

It was strongly indicated by the APA that SM would be subsumed into Social Anxiety Disorder (SAD) in the DSM V (APA, 2013) in May 2013. However, potentially as a result of objections made to this intention during public consultations in 2012 (e.g. see NICE, 2013), the APA withdrew this change shortly prior to publication, which illustrates that there is still some uncertainty regarding the relationship between SM and SAD, despite the high level of comorbidity of both conditions (discussed in section 7.4.2). This decision, and the relationship between SM and SAD, will be evaluated by this research.

7.1.1. The history of SM in relation to adults with SM

The DSM IV-TR (APA, 2000) correctly indicated that SM can continue into adulthood. Public perception, however, which is due to the majority of research on SM being done on children, is that SM is a condition solely of childhood and of *young* childhood at that. The DSM V (APA, 2013), by moving SM to the group of anxiety disorders and out of the miscellaneous category of disorders first diagnosed in infancy, childhood, and adolescence - along with works like this current research - may, in time, help to change public perception somewhat.

The DSM V (APA, 2013) also indicates the total lack of longitudinal studies of SM, in order to discern long-term outcomes of SM, which is a further rationale for this research. While this is a cross-sectional study, it is about a section of people with SM (adults of all ages) who have never been researched or, as it were, been given a ‘voice’ or say in the presentation or understanding of their own condition before.

Significantly, also, the DSM V (APA, 2013) drops reference to extreme psychosocial stressors being a possible cause for SM as it has previously been suggested to be (e.g. Dow, Sonies, Scheib, Moss, & Leonard, 1995; Krohn, Weckstein, & Wright, 1992). The DSM V (APA, 2013) makes much more emphasis of predisposing to precipitating factors.

Additionally, it indicates an equal gender distribution whereas DSM-IV-TR (APA, 2000) indicates that marginally more females have SM.

Past research has generally shown a female-biased variation in the female:male ratios of SM in children of: 2.4:1 (Wright, 1968); 2.1:1 (Ford, Sladeczek, Carlson, & Kratochwill, 1998); 2:1 (Wilkens, 1985; Wergeland, 1979; Hayden, 1980); 1.7:1 (Tancer, 1992); 1.6:1 (Steinhausen & Juzi, 1996); 1.1:1 (Kolvin & Fundudis, 1981); and 1:1 (Elizur & Perednik, 2003; Bergman, Piacentini, & McCracken, 2002; Kopp & Gillberg, 1997).

7.2. Selective mutism speech patterns

The definition of SM in DSM V (APA, 2013) is still - as were previous versions - biased towards a speech pattern where a child cannot speak at school but can at home, which is an often-used stereotype in many introductions to studies on SM (e.g. see Manassis & Avery, 2013; Gordon, 2001; Anstendig, 1999; etc.) The demarcation of speech versus non-speech situation is seldom so clear cut, however – many children, similarly adults too, with SM, not being able to speak to visitors, including second-degree relatives, in their home environment (Mulligan, 2012).

The Selective Mutism Questionnaire (Bergman, Keller, Piacentini, & Bergman, 2008) accommodates variant speech patterns in various environments and settings - including at home, with or without strangers present. Speech inhibition often extends to step-parents within the home; and occasionally to first-degree relatives also, such as the father or less often the mother.

It is more difficult to argue that SM is a *social* anxiety disorder, which Black and Uhde (1992) suggest, when speech behaviour extends to first-degree relatives, even if this variation in speech pattern is ostensibly rare. As an example, Motavelli (1995) refers to a 12-year-old girl who had not spoken to family members since age 4.

7.3. The formal diagnostic criteria for Selective Mutism

SM is a psychological or psychiatric condition, deemed an anxiety disorder in the DSM V (APA, 2013), in which a child or adult is mute, or experiences significant psychological difficulty in speaking, presenting as very significant speech reticence, in one or more non-performance-related social situations.

The diagnostic criteria for SM in the DSM V are (APA, 2013, p. 195):

A. “Consistent failure to speak in specific social situations in which there is an expectation for speaking (e.g., at school), despite speaking in other situations.”
B. “The disturbance interferes with educational or occupational achievement or with social communication.”
C. “The duration of the disturbance is at least 1 month (not limited to the first month of school).”
D. “The failure to speak is not attributable to a lack of knowledge of, or comfort with, the spoken language required in the social situation.”
E. “The disturbance is not better explained by a communication disorder (e.g., childhood-onset fluency disorder) and does not occur exclusively during the

> course of autism spectrum disorder, schizophrenia, or another psychotic disorder."

From experience (the researcher himself did not receive a diagnosis of SM in childhood) most adults with SM will not have received a diagnosis. As such, many participants will have self-diagnosed using the above criteria and/or other research articles that they will have read about SM (most of which refer to SM in children.)

7.4. The aetiology and functional aspects of SM

While SM has certain diagnostic criteria, the current research intends to investigate both the aetiology and, relatedly, the functional aspects of SM – i.e. what function does silence serve for the child or adult with SM? Is SM an instinctual response (like the freeze defence response in animals)? Is SM (as the DSM V (APA, 2013) suggests it to be) an anxiety disorder per se? And is SM a social anxiety disorder?

SM was first written about by Kußmaul in 1877; and was just one of many other discoveries he made from dyslexia (Smythe, 2011) to vasculitis (Matteson, 2012). As a condition of long-standing which has been puzzling for clinicians to explain ever since, various interpretations of SM have been put forward to explain it, each of its time. Rather than simply prefer one kind of explanation over another, the current research intends to synthesize what may have been right with each kind of interpretation. As such the research design shall incorporate questions to evaluate and synthesize differing interpretations of SM.

7.4.1. Selective Mutism versus Freeze Defence and Attachment

While the terminology is now outmoded among psychologists, SM could be conceptualized as a stranger reaction (Lesser-Katz, 1988) and contrasted with "freeze defence" in animals (Lesser-Katz, 1986). Alternatively SM could also be seen to be an anachronistic expression, as indicated by Shreeve (1991), of similar reactions to those seen in the Strange Situation (Ainsworth & Bell, 1970; Ainsworth, Blehar, Waters, & Wall, 1978). Thus, SM may have a relationship with attachment behaviour (Bowlby, 1958; Bowlby, 1982 / 1969). For instance, childhood caregiver separation, through hospitalization, is sometimes indicated in SM (e.g. Louden, 1987). In particular, the stereotypical speech pattern for SM (being mute at school / away from the caregiver) is said to be reminiscent of an insecure attachment style (Kolvin, Trowell, Le Couteur, Baharaki, & Morgan, 1997).

Based upon such interpretations of SM, attachment style differences may also explain some of the individual variations in speech patterns (i.e. patterns of who can and cannot be spoken to) between sufferers of SM. Some sufferers of SM - particularly those who experienced triggers, or significant disruption in their childhood family environment – may, hypothetically, demonstrate more leaning towards an avoidant attachment style; and this may manifest itself as a different speech pattern in which first-degree relatives cannot be spoken to.

7.4.2. Selective Mutism versus Social Anxiety Disorder (SAD)

In the DSM V (APA, 2013) SM is classified as an *anxiety disorder* for the first time. This change was backed by a body of research which demonstrated anxiety to be a key component of SM (e.g. Anstendig, 1999; Vecchio & Kearney, 2005; Sharp, Sherman, & Gross, 2007; Reuther, David, Moree & Matson, 2011; Levin-Decanini, Connolly, Simpson, et al., 2013; etc.)

Furthermore, many further works indicate the commonality between SM and SAD (Scott & Beidel, 2011; Bögels, et al., 2010; Cunningham, McHolm, & Boyle, 2006; Dummit, et al., 1997; Black & Uhde, 1995; Black & Uhde, 1992). Such research led to the conclusion, amongst many researchers, that SM may be a specific type of early-onset SAD. It was on this basis that SM was to be subsumed into SAD until shortly before publication of the DSM V (as previously discussed.)

More often than not, those existing works describing the differences between SM and SAD emphasise learning or language difficulties, or developmental delays in SM, which are not present in controls, or those with SAD (Yeganeh, Beidel, & Turner, 2006; Manassis, et al., 2003). Similarly, Cohan, et al. (2008) cite differences in expressive and receptive language abilities and mild behavioural problems in children with SM, compared to controls. On the other hand, Nowakowski, et al. (2009) demonstrated that children with SM attain vocabulary and academic abilities entirely expected for their age; hence “ability” is, therefore, not the issue for many children with SM.

Thus, in summary, the evidence suggests that there are likely to be subgroups of children with SM – some with speech and language difficulties, some with developmental delays or disorders, and others with neither. The difference between SM and SAD therefore, if such a difference exists, is not likely solely to be based upon learning or language deficits.

Moreover, when speech inhibition extends to first-degree relatives (as in Motavelli, 1995), it is much more difficult to argue that SM and SAD are the same. Emotional processes, other than social anxiety or shyness, are involved when SM extends to first-degree relatives. This would suggest that describing SM as SAD cannot cover all cases of SM; it may also suggest that, in some cases, SM is not an anxiety disorder also per se. A full understanding of the reality of SM, in *every* case, may require a mixture of older and newer conceptions of the disorder.

7.4.3. Selective Mutism as a Safety Behaviour

A conceptualization which neatly subsumes the conceptualization of SM as a stranger-reaction *and* SM as an anxiety disorder *and* SM as a candidate social anxiety disorder is the suggestion that SM is a form of safety behaviour. For an overview of situational safety behaviour see Salkovskis (1991; 1996; 1999) or Rachman, et al. (2008).

If one accepts SM to be a form of safety behaviour, as social anxiety is (Rachman, Radomsky, & Shafran, 2008), and agoraphobia and panic disorder are (Salkovskis, Clark, Hackmann, Wells, & Gelder, 1999), one can subsequently search for functional purposes of silence, in relation to 'safety' in given situations: for example regulating anxiety

(Moldan, 2005); or avoiding anxiety (Young, Brian, & Beidel, 2012); masking language or speech deficits (McInnes, Fung, Manassis, Fiksenbaum, & Tannock, 2004; Manassis, et al., 2003); masking developmental delays (Cleater & Hand, 2001; Kristensen, 2000; Kolvin & Fundudis, 1981); avoiding scrutiny of the observable self (Pujol, et al., 2013; Roth & Heimberg, 2001); manipulating others, consciously or otherwise, via silence, to create or maintain safety (Anstendig, 1998); as part of an enmeshed relationship with a primary caregiver (Wong, 2010) in which silence mutually serves both the caregiver and child – along the lines of symbiotic mutism (Hayden, 1980); as an automatic reaction to witnessing domestic abuse, along the lines of reactive mutism (Hayden, 1980); as a form of antisocial or oppositional behaviour (Giddan, Ross, Sechler, & Becker, 1997; Wright, Cucearo, Leonhardt, Kendall, & Anderson, 1995); etc.

As suggested by the above list of possible *functions* of SM, SM is a complex, multidimensional behaviour centred upon communication, derived from complex social communicative 'transactions' over a long period of time (Cohan, Price, & Stein, 2006).

As such, a gene × environment (G × E) interaction (e.g. Nugent, Tyrka, Carpenter, & Price, 2011) may explain SM. Every individual with SM may experience manifold reasons for silence across the duration of the disorder. No one 'reason' for muteness may even describe the experience of a single sufferer of the condition. The research design thus included opportunities for multiple reasons for muteness to be identified for every participant that took part.

Safety behaviours may implicate individual differences in brain biology – specifically in functioning of the amygdala and the hippocampus (e.g. McHugh, Deacon, Rawlins, & Bannerman, 2004; Buchanan, 2007; Satpute, Mumford, Naliboff, & Poldrack, 2012). SM is, often, of such long duration that the behaviour long outlives the original stimulus, if there is a stimulus at all. Obmutescent behaviour is incredibly repeatable in any given specific situation, or like situation, over many years. The current research shall investigate this by incorporating into its design, items to discern whether speech pattern changes over time – the hypothesis being that, on the whole, it does not.

The amygdala is also implicated in autism (e.g. Baron-Cohen, et al., 2000), and comprises part of the "social brain". As such, given the intricate relationship between one's social self, one's method of appraisal of others, one's ability to tolerate appraisal and scrutiny from others, and speech, it can be very difficult to separate SM from SAD from ASDs from deficits in social interaction or communication.

It should also be noted that safety behaviour is also an aspect of eating disorders (Waller & Marcoulides, 2013).

SM is a common comorbidity of Asperger Syndrome (Wolff, 1995; Gillberg, 1989; Andersson & Thomsen, 1998). Similarly eating disorders, particularly anorexia nervosa (AN), are common comorbidities of AS and other ASDs (Rastam, Gillberg, & Wentz, 2003; Hambrook, Tchanturia, Schmidt, Russell, & Treasure, 2008). ASDs and AN (particularly AN with childhood onset) have already been linked via shared social-cognitive features

(Oldershaw, Treasure, Hambrook, Tchanturia, & Schmidt, 2011; Odent, 2010); however the link has yet to be made between SM and AN but warrants future research because of the functional symmetry between SM and AN. Simply put, the researcher suggests that AN is to food intake as SM is to 'social' intake (particularly social intake in the form of scrutiny of the inner self.) This analogy will be investigated further in the discussion.

The research shall investigate the comorbidities of SM, expecting there to be a high level of comorbidity with other anxiety disorders, other safety behaviours (e.g. AN), and mood disorders.

Regarding current areas lacking research, there appear to be no studies on situational safety behaviour versus SM; the prevalence of SM in ASDs; or the prevalence of eating disorders (particularly AN) in SM. Clearly therefore research on SM is still in its early stages despite SM being a "known" condition since 1877. For future researchers, with the means to undertake genetic research, the author hypothesizes a genetic relationship between SM, ASDs, eating disorders (particularly AN), and SAD.

7.5. Genetics and SM

There is scant research on genetics in SM to date, SM being seen as a rare disorder. However, Stein et al. (2011) suggest a susceptibility to SM via specific variation of the CNTNAP2 gene. This is a gene which is also implicated in Gilles de la Tourette syndrome, major depression, schizophrenia, epilepsy, autism, and ADHD. Rupp (1999) previously suggested Tourette's has a potential relationship with SM. There are also a few studies relating to SM as an uncommon antecedent to schizophrenia (Waldo, 1999; Eldar, Bleich, Apter, & Tyano, 1985), and there are also potential links between SM and Fragile X syndrome (Haggerman, Hills, Scharfenaker, & Lewis, 1999). Likewise, there are, also, potential links between 22q11-deletion syndrome and SM (in Kristensen, 2002). Toma, et al. (2012), however, failed to replicate an association between variants of the CNTNAP2 gene and autism susceptibility or language traits.

Clearly, the genetic aspects of SM and its relationship with other disorders and behaviours is a major future area of research and few conclusions can be drawn yet. However, it may well be that there is, at least partly, a genetic and biological basis for SM, regardless of the complexity of SM as a behaviour. For instance, Black and Uhde (1995) reported that 37% of first-degree relatives of children with SM had a history of SM.

General psychiatric problems in parents of children with SM are said to be widespread (Kolvin, Trowell, Le Couteur, Baharaki, & Morgan, 1997).

While the current study is exploratory and does not involve genetics one of the hypotheses of this research shall be that SM is, at least in part, due to a G × E interaction: i.e. is a mixture of genetics and environment.

7.6. Previous research on SM

There are scant first-hand accounts of SM in either academic or popular literature, not least because of the nature of the condition – i.e. children, who have almost exclusively been the focus of research in SM until this point, generally being unable to directly communicate with psychologists or researchers. Adults with SM are also extremely reluctant to spotlight themselves.

Although SM is now classed as an anxiety disorder in DSM V, the diagnostic criteria do not specifically describe what SM *is* and how it affects people. Rather they describe a clinical model of presentation of symptoms for the purposes of diagnosis. Regarding what SM *is*, in terms of the effect it has on children and adults, the most informative source should be, of course, sufferers of SM themselves.

The few phenomenological research studies which exist are: Omdal (2007) who interviewed adults directly who had had SM in childhood and adolescence but were now recovered; Omdal and Galloway (2007) who, indirectly, interviewed children with SM using a projective method (i.e. via writing a story) while attempting to avoid reinforcing mutism in doing so; Roe (2011) who researched the views of teenagers with SM via questionnaires sent to parents in contact with SMIRA (http://www.smira.org.uk); and Patterson (2011) who used Personal Construct Theory (Kelly, 1955 / 1991) to explore personal experiences of SM in teenagers, again via parents in contact with SMIRA.

Omdal (2007) is notable in some of the participants of this research indicated significant environmental (i.e. abusive) triggers which caused their SM; whereas most other studies, including Roe (2011) indicated that such triggers, when they existed at all, were small.

This research is therefore the first to *directly* ask current sufferers of SM (all *adults* with SM) what they perceive SM to be, and to ask them how it affects them *now* and how it personally affected them in the past.

7.6.1. SM in adults

Regarding research specifically on adults with SM, there are only a few miscellaneous references to adults with SM and individual case studies in existence (none of them widely cited). For instance Kehle, et al. (2012) refer to a 44-year-old American woman who had not spoken to anyone besides her mother for more than 37 years; Bankier, et al. (1999) describe comorbid SM in a 25-year-old man with AS; Pavlek (2001) discusses a ‘mildly retarded’ man, aged 50, who ‘elected’ to be mute for 28 years; Patti and Tsiouris (2003) refer to a 28-year-old woman with Down syndrome and SM; and Jainer, Quasim and David (2002) refer to a 22-year-old young woman with SM.

There are also individual case studies of adults with SM in other cultures: Babikian, et al. (2007) refer to a Nepalese soldier with SM, and Hollifield, et al. (2003) refer to a Vietnamese man with SM. Bradway (1937) also refers to a young Mongolian woman with *hysterical* mutism – likely to be SM. Individual case studies on SM in adults lean towards reporting the novelty and rarity of the condition in adulthood; and one could also argue with the language of a few of the studies which include the words ‘imbecile’ (Bradway, 1937) and ‘retarded’ (Pavlek, 2001).

Ford, et al. (1998) included 18 adults who had SM at the time of taking part in the study (or in the past, it is somewhat unclear which) in an overall sample of 153 participants. The major drawback of this study, however, is that 144 of the responses were completed by a third party - such as a parent. This was necessary because the majority of participants were children. Only nine questionnaires were completed by sufferers of SM themselves. Questionnaires from the other nine adults (presumably young adults) were completed by their parents.The current study is thus invaluable therefore, because it is the first study to exclusively receive answers directly from current sufferers of SM.

7.6.2. SM in adults in the news and in popular culture

SM in adults occassionally appears in the news for the "wrong reasons". For example, Seung-Hui Cho was a young adult with a diagnosis of SM who perpretrated the Virginia Tech massacre in 1997 (Kearney & Vecchio, 2007; O'Connell & Moldan, 2013); and Adam Lanza, also an adult thought to have SM, perpetrated the Sandy Hook Elementary School shooting in 2012 (see O'Connell & Moldan, 2013). Of course such eventualities are *very* rare outcomes for young adults with SM, but they demonstrate that SM is not just a twee condition which affects children.

Regarding other news items on adult SM, an unknown proportion of adult Hikikomori in Japan (e.g. see Kremer & Hammond, 2013) have SM and / or autism. The proportion of Hikikomori who are males are said to way outnumber those who are females, but social expectations in Japan are such that females are often sequestered anyway.

Jennifer and June Gibbons were twins, mute with everyone but each other, who committed petty crimes until they set fire to a petrol station. They were, subsequently, incarcerated in Broadmoor (Wallace, 1996).

Portrayals of adult SM and mutism have also been presented in popular culture – e.g. the play 'Speechless' (Teale, Brogan, & Wallace, 2010), the play and film 'The Rise and Fall of Little Voice' (Cartwright, 1992), the film 'The Piano' (Campion, 1993), the film 'Birdy' (Parker, 1984), and the character Raj in 'The Big Bang Theory' (CTV, 1997-). There are also a few other films about SM in children: 'Trapped in Silence' (Atkins, 1986) based upon Torey Hayden's 'Murhphy's Boy' (Hayden, 1983) and 'The Quiet Room' (de Heer, 1996).

It should also be mentioned that self-publishing is also currently being used by a small number of adults and adolescents to express their personal experiences of SM. See Thorpe (2011) for instance. Some participants found this study after reading Jessica Thorpe's autobiography, recognising so much of themselves in it. YouTube is also another way that adolescents and young adults with SM are making their experiences known - often by holding up hand-written cards rather than speaking. Notably, most adolescents and young adults often rationalize SM as a severe form of SAD. For instance see Colón (2010) or Wilson (2012.) Other adults with SM sought this study after watching a number of relatively recent documentaries on SM in children: for instance 'My Child Won't Speak' broadcast on the BBC in 2010 (BBC, 2010; Hewitson, 2010), and 'Help Me To Speak' broadcast on Channel 4 in 2006 (Dawson, 2012).

As such there has been a large increase in the portrayal of SM in recent years, giving rise also, to an increase in awareness of SM – among sufferers of SM also, who were formerly unaware that there was a name for what they had suffered with for years. Personally, in the researcher's young adulthood (which was pre-internet), the only literature / story he had which was in any way reflective of his own experience was that was that of Jennifer and June Gibbons, along with one article by Torey Hayden (Hayden, 1980) which he located in the university library. Nowadays, awareness of SM and the level of easily accessible information, is very different. The main reason for this is the internet.

7.7. Long-term outcomes of SM and rationale for the current study

Ford, et al. (1998) indicate that the mean cessation age for SM, for those that do recover, is 7.6 years old. Given that the cessation of symptoms often occur so early on, there have been few attempts to evaluate long-term outcomes of SM for those that continue with SM into adolescence or young adulthood, even though such studies are often called for (e.g. in Storgaard & Thomsen, 2003; Standart & Le Couteur, 2003). The DSM V also indicates a need for such studies (APA, 2013, p. 196): "the longitudinal course of the disorder is unknown."

To date, long-term outcome studies have only been undertaken twice: by Remschmidt, et al. (2001) and more recently by Steinhausen, et al. (2006). Remschmidt et al. evaluated 45 patients (23 boys and 22 girls) with Elective Mutism (EM) at two ages: when they were 8.7 ± 3.6 years old, then 12 years later when they were young adults. According to

Remschmidt et al. (2006), 25 out of the 41 young adult patients (61%) still had some level of communication difficulty. Steinhausen et al. (2001) evaluated a sample of 33 young adults who had received a prior diagnosis of SM in childhood, and suggested wholesale symptomatic *improvement* of SM by young adulthood.

Table 1 — Meta-analysis to determine the potential incidence of young adults with SM

Have SM between 7-15		
≈1 in 555 children (Kopp & Gillberg, 1997)		
Remission by young adulthood	Unmasked communication problems, having had SM in childhood	Speech reticence or SM in young adulthood
39% (Remschmidt, Poller, Herpertz-Dahlmann, Henighausen, & Gutenbrunner, 2001)	< 38% (Steinhausen & Juzi, 1996)	> 23%
≈1 in 1400 young adults	< ≈1 in 1500 young adults	> ≈1 in 2400 young adults

Steinhausan and Juzi (1996) reported that 38% of children with SM are said to be masking a genuine speech-language difficulty, perhaps being embarrassed to speak for that reason. Taking that into account, Remschmidt et al.'s (2006) data, and Kopp and Gillberg's (1997) incidence rate of SM in childhood, it is therefore possible to derive a *very* rough estimate of young adults with SM as given in Table 1.

Thus, if there are 50 million adults in the UK (UK National Statistics, 2013) then there *may*, in theory, be more than 20,000 adults with significant speech reticence and SM in the UK, an unknown proportion of whom still experiencing full-blown SM at a clinical level. Contrast this with 540,000 adults who are said to have autism spectrum disorders

(The National Autistic Society, 2013), including Asperger syndrome (AS), and it may be that 20,000 is an underestimate, particularly in light of SM anecdotally being said to often be comorbid with AS. It is therefore curious why there has been no specific research on SM *in adults* undertaken until this point, either in the UK or anywhere else in the world.

7.8. The current study

In summary therefore, despite calls for research on SM in adults (e.g. in APA, 2013), no cross-sectional research on adults with SM using the information provided by adults with SM themselves, has ever been undertaken until this point. This is despite the fact that adults with SM may be able to say more about SM, the condition and its outcomes, than anyone else.

As indicated previously, the DSM V (APA, 2013) includes SM as an anxiety disorder for the first time, having moved it from a condition of childhood or adolescence. Additionally the DSM V also refers to adults with SM explicitly, and states there to have been no cross-sectional research on adults. It is, therefore, an important time to do this current research in order to discern whether adults with SM perceive SM to be an anxiety disorder and, more simply, to confirm their existence.

The DSM V (APA, 2013) has also made other changes from the DSM-IV-TR (APA, 2000), such as indicating that SM occurs equally in males and females. The DSM V (APA, 2013) has also removed all emphasis on causation for SM, including SM occurring as a result of extreme psychosocial stressors. An aim of the research is to challenge these two changes.

7.8.1. Study design and hypotheses

It is unlikely that this research could have been undertaken prior to the advent of the internet. As such the research was conducted via online questionnaires advertised on a number of websites where adults with SM were expected to see it, namely: iSpeak.org.uk and SelectiveMutism.org.

The majority of the hypotheses are exploratory. They are, however, based upon the life-experience of the researcher as an adult sufferer of SM. Thus while the current study was exploratory it was conducted with a certain amount of pre-knowledge requiring further substantiation.

H1 – SM is not solely a childhood disorder

H2 – SM occurs more frequently in adult females than adult males

H3 – The mean age of onset of SM will be before 4 years, based upon research on SM in children

H4 – Most sufferers of SM will not have received a formal diagnosis

H5 – There will be high levels of comorbidity in adults, particularly with other anxiety-related psychopathologies and eating disorders

H6 – The severity of SM will slowly reduce with age

H7 – SM is not limited to school / educational settings

H8 – SM is not a form of SAD, but is often comorbid with / develops into SAD

H9 – SM is the result of a G × E interaction, hence is partly genetic

H10 – SM in adults is not limited to western cultures (i.e. is worldwide, unlike Anorexia Nervosa)

8. Method

8.1. Participants

Eighty three adults, who described themselves as having SM after age 18, including seventy nine who still described themselves as still having SM, took part in this research. Participants were aged between 18 and 64, with a mean age of around 33. A ratio of approximately 4:1 females to males took part in the current research.

In line with the original research proposal (see Appendix A), participants were invited to take part though an invite and participant information sheet (see Appendix B) which were posted online on a number of websites where adults with SM were expected to see them – e.g. http://www.ispeak.org.uk, and http://www.selectivemutism.org. Participants were also directly invited to take part by an e-mail sent to all members of the researcher's own online support group for adults with SM: http://www.ispeak.org.uk (a small online organization linked to by NHS Choices.) Participants were also recruited by word-of-mouth by SMIRA (http://www.smira.org.uk). Additionally, an advertisement video was posted on YouTube (the advert is contained on the CD in Appendix H.)

8.2. Measures

The study involved the use of two bespoke questionnaires, designed by the researcher - based on his own personal experience of SM and, also, his experience as the provider of online support and advice to numerous parents of children with SM, and adults and teenagers with SM via http://www.ispeak.org.uk.

The questionnaires were created in Adobe FormsCentral (Adobe, 2012) for completion either online (as a web form or PDF form), or to print and return to Chester University addressed to the researcher.

The questionnaires were trialled by a couple of adults with SM personally known to the researcher (who suggested some important modifications); and were also informally appraised by experts in the field including Maggie Johnson (of Johnson & Wintgens, 2001). Questionnaire 2 was created less than a month into data collection, when the researcher began to receive more responses than expected and realized that statistical comparisons between SM, shyness and social anxiety may be possible. The original research proposal (Appendix A) had only hoped for around 10 participants. If this research were repeated, amalgamating both questionnaires would be appropriate.

The questionnaires were designed to support an exploratory study; as such while they were directed towards evaluating the hypotheses (section 7.8.1), they also included open-ended items where the participants could express their experience in as much depth as they wished to. The structure of the questionnaires are given below in Table 2 and Table 3. The questionnaires themselves are given in Appendix C and Appendix D respectively.

The questionnaires were designed to be completed (by skipping open-ended questions) in as little as 20-30 minutes. They were design to collect more in-depth information also, however, for those who felt able to do so. Many participants committed to spending considerably longer on their answers - spending a few weeks and, in a few instances, a few months providing extremely detailed and substantial answers to the questionnaires. Additionally, participants provided life stories which augmented the open-ended items in the questionnaires. The commitment of the participants to the questionnaire is to be lauded; it was clear that taking part meant a great deal to most, if not all, of those that did so.

Table 2 — Structure of / items contained in Questionnaire 1

This questionnaire was designed to collect information about experiences of SM	
Introduction	Included information about the study, indicated who should take part in the study (i.e. adults who still experienced SM when turning 18), information about helplines to use if taking part in the study proved to be unexpectedly distressing, and information regarding withdrawing data without explanation if the participant wishes to. This section additionally contained the departmental address which could be used to print and submit the questionnaire in the post, if so preferred.
Section 1	Consent to take part, consent to subsequently be contacted again if necessary, and country in which the participant lived
Section 2	Basic details – gender, current age, age of onset, age of realization of difference, measures of severity of SM at different ages, questions relating to how sufferers perceive SM (e.g. what they believe it to be, such as a form of social phobia), and how SM has affected them in various domains (using likert scales.) This section is interspersed with ample opportunity for sufferers of SM to provide in-depth information via open-ended questions.
Section 3	Childhood & adolescent experience of SM – including speech pattern (who could and could not be spoken to at age 10), whether participants experienced triggers, and comorbidities they experienced in childhood. This section was interspersed with ample opportunity for sufferers of SM to express their childhood experiences in relation to SM.
Section 4	Adult experience of SM – including speech pattern (who could and could not be spoken to at age 18, and 'now'), comorbidities experienced in adulthood. This section was interspersed with ample opportunity for sufferers of SM to express their adult

	experiences in relation to SM, and to suggest reasons why their SM continued into adulthood.
Section 5	Attitudes towards and experiences of help, both in childhood and adulthood – including means for participants to feedback on their experiences of professional help, how their parents, friends, relatives, helped them (or did not help them), and so on.
Section 6	An invitation to send further information in the form of a life story via e-mail to the researcher.
Section 7	A section asking for feedback about the research questionnaire, and for ideas that participants may have regarding future research in relation to SM. And a button to submit the questionnaire electronically, and to automatically receive an acknowledgement that the data has been received.

Table 3 — Structure of / items contained in Questionnaire 2

This questionnaire was designed to collect information about SM in relation to shyness and social anxiety disorder / social phobia	
Introduction	Included very similar information to the introduction of Questionnaire 1, with an additional explanation of why participants might wish to take part in a follow-up questionnaire – i.e. to evaluate the relationships (or lack of relationships) between SM, shyness, and social anxiety disorder / social phobia.
Section 1	Consent to take part in Questionnaire 2.
Section 2	SM in relation to shyness – including a self-reported measure of the perceived severity of shyness at different ages, an explicit multiple-choice item regarding the relationship between shyness and SM, and an open-ended question for participants to air their thoughts on the relationship.
Section 3	SM in relation to social anxiety / social phobia – including a self-reported measure of the perceived severity of social anxiety at different ages, an explicit multiple-choice item regarding the relationship between social anxiety and SM, and an open-ended question for participants to air their thoughts on the relationship.
Section 4	An open-ended question where participants could air their thoughts on the relationship between SM and other conditions.
Section 5	A button to submit the responses electronically, and to automatically receive an acknowledgement that the data has been received.

8.3. Procedure

The questionnaires were made available online for data collection between Tuesday January 9th 2013 (the date of ethical approval) and Friday May 3rd 2013. A lengthy data collection period was required to maximize participation.

Every participant who completed Questionnaire 1 who indicated that they were happy to be contacted again, was personally invited via e-mail by the researcher to also complete Questionnaire 2.

Data were transferred from Adobe FormsCentral (which automatically electronically captured the data, besides for those who posted their results) to SPSS and NVIVO using bespoke software written by the researcher using Adobe Acrobat XI Pro, Microsoft SQL Server, and Microsoft Visual Studio 2012. When participants posted their results, the researcher manually entered the data received into Adobe FormsCentral.

Extra columns were computed in SPSS directly. The information on this procedure is given in Appendix E.

8.4. Design and analysis

As an exploratory study, the research does not consist of a single design. Rather, multiple designs and a large number of analyses and multiple types of analysis (both quantitative and qualitative) were undertaken to fulfil evaluation of the hypotheses described in section 7.8.1. Additionally, as an exploratory study, the measures were such that other information outside the hypotheses could also be collected and reported or analysed. Every SPSS script used for quantitative analysis is detailed in Appendix F. Some analyses which were conducted but which were outside the scope of the hypotheses and also outside the main gist of the discussion are given in Appendix G. Every output file from SPSS is contained on the CD in Appendix H. Table 4 details the design and some of the analyses used to fulfil evaluation of the hypotheses.

Table 4 — Study designs / analyses in relation to the hypotheses

Hypothesis	**Design / analysis**
H1: SM is not solely a childhood disorder	No design as such – the fact that participants took part, combined with the researcher's personal experience, indicates that SM is not solely a childhood disorder. However, frequency information would be used to demonstrate the existence of adults with SM.
H2: SM occurs more frequently in adult females than adult males	Frequency information would be used to demonstrate that more females than males took part in the questionnaire.
H3: The mean age of onset of SM will be before 4 years, based upon research on SM in children	Simple descriptives would be used to evaluate the mean age of onset. Independent-samples *t*-tests would be used to evaluate differences by gender etc.
H4: Most sufferers of SM will not have received a formal diagnosis	Participation in the study did not require diagnosis. As such there was no explicit question asking whether a participant had received a diagnosis; rather, collecting data about rates of diagnosis was done via thematic analysis. *t*-tests would be used to evaluate age group differences between receiving diagnoses. Simple descriptives would be used to contrast diagnosis rates between countries (the study being open world-wide.)
H5: There will be high levels of comorbidity in adults, particularly with other anxiety-related psychopathologies and eating disorders	χ^2-tests would be used to evaluate gender differences, for instance, between reported anxiety disorders in childhood and adulthood. Additionally, χ^2-squared tests would be used in conjunction with publicly available mental health related data (e.g. Bebbington, et al., 2007) to contrast the comorbidity between SM and other conditions in adulthood in the general population.
H6: The severity of SM will slowly reduce with age	Every participant provided up to 14 self-reported, retrospective measures of the severity of their SM at different ages. Simple descriptives between subjects for each of the 14-ages would discern the general trend. *t*-tests were used to contrast, for instance, gender differences between subjects.

H7: SM is not limited to school / educational settings	Participants reported the same set of yes/no answers regarding to people/types of people that could and could not be spoken to at three different ages. χ^2-squared tests would be used to contrast speech pattern between ages, within subjects. Additionally binary logistic regression were used to evaluate predictors of being mute in any given situation.
H8: SM is not a form of SAD, but is often comorbid with / develops into SAD	Participants provided both up to 14 self-reported retrospective measures of the severity of their SM at different ages, along with up to 14 self-reported retrospective measures of their SP at the same ages. Repeated measures (paired-samples *t*-tests) would be used to contrast SM with SP at each age group between subjects. Additionally, a split-file technique would be used to contrast groups of participants. Given SM, Shyness and SAD measures were DVs, more complex (e.g. 3-way repeated measures mixed design ANOVAs) could not be undertaken.
H9: SM is the result of a G × E interaction, hence is partly genetic	This hypothesis would primarily be evaluated via thematic analysis, relying on the expressed experiences of adults with SM regarding the environmental factors which were involved in their experience. Whether factors are highlighted, quantitative analysis on an ad-hoc basis could be undertaken.
H10: SM in adults is not limited to western cultures (i.e. is worldwide, unlike Anorexia Nervosa)	Given the questionnaire was opened “world-wide” (though mostly advertised in English-speaking countries by virtue of being hosted on English-speaking websites), simple frequencies of response, in conjunction with the literature review, shall be able to demonstrate the likelihood of this hypothesis.

8.5. Ethical considerations

The study was undertaken entirely to BPS guidelines. Due consideration was given to the wellbeing of everyone who took part. The questionnaires and method of data collection were given ethical approval by the Ethical Committee of the University of Chester Psychology Department prior to commencement of data collection.

Participants were permitted to withdraw their data at any point from submitting it until the end of the data collection period. Additionally, participants were advised not to take part if they felt it may be detrimental to their emotional wellbeing; and were given helpline numbers - and particularly important for people with SM - helpline e-mail addresses to use if they were distressed by taking part. No participant withdrew their data however, and it was clear from the comments given that many of the participants welcomed the research and felt the emotional benefit of finally being able to anonymously air their stories.

The data retained were anonymised. At all points the data were stored safely, in accordance with BPS guidelines. Regarding locality and other personal information only country of residence at the time of completing the data were collected, which enabled an interesting statistical comparison of diagnosis rates between the UK and the USA.

9. Results

The overall aim of this study was to evaluate the experiences of adults with SM. As such it is an exploratory study and many of the statistics will be in the form of descriptives.

In order to assist reading and interpreting of the results, a cross reference between questionnaire items, variables, and an explanation of how other variables were computed / how the data were prepared, is provided in Appendix E. Additionally, Appendix F contains all SPSS scripts used to perform each analysis. Finally, Appendix H includes a CD containing the SPSS data files, all SPSS output files, along with text used for thematic analysis and other information such as the .mp4 video advertisement for the study.

Statistical analyses were undertaken using SPSS Version 21. Thematic analyses were undertaken using NVIVO 10.

The results are shown in two sections: section 9.1 includes analyses relating to the hypotheses and section 9.2 includes interesting findings, not relating to the hypotheses, which are discussed further. Additionally, some analyses which are still noteworthy but ancillary to the discussion are included in Appendix G.

Throughout the results section a significance level of <.05 is marked with *; a significance level of <.01 is marked with **; and a significance level of <.001 is marked with ***.

9.1. Analyses and findings related to the hypotheses

This section contains analyses organized by hypothesis, each of which is evaluated in turn.

9.1.1. SM is not solely a childhood disorder (H1)

Eighty three adults, aged 18-64, who described themselves as having SM while turning 18, participated in this study, with a mean age of ≈33.4.

The mean age will be used in a number of subsequent statistical analyses to contrast "younger" and "older" participants. There were 51 participants younger than age 33.4 and 32 older.

Table 5 shows recovery rates by current age group. The maximum age of a participant who said he or she had not found any improvement in their SM symptoms was 46†

Table 5 — Improvement and recovery by age-group

Age group	**Recovered**	**Partially recovered**	**Not improved**	**Total**
18-20	0	6	3	9
20s	1	21	8	30
30s	1	14	5	20
40s	1	10	1†	12
50s	1	9	0	10
60s	0	2	0	2
Total	4	62	17	83

Table 6 shows the recovery rate of participants for this study. It is interesting to note, however, that of those that said they had recovered, all were females.

Table 6 — Recovery rates of participants by gender

Gender	Recovered	Partially recovered	Not improved
Male	0	13	4
Female	4	49	13
(Total)	4	62	17

9.1.2. SM occurs more frequently in adult females than adult males (H2)

Table 7 — Gender and age-ranges of participants

Gender	N	Percent	Min / max age	Mean age (SD)
Female	66	79.5%	18 / 64	33.11 (12.64)
Male	17	20.5%	18 / 64	34.71 (14.64)
(Total)	83	100.0%	18 / 64	33.43 (13.00)

As shown in Table 7, there was a ratio of approximately 4:1 females to males with SM.

Table 8 — Frequency of participants per age-group by gender

	Both genders		Male		Female	
	N	Percent	N	Percent	N	Percent
18-20	9	10.8%	1	1.2%	8	9.6%
20-29	30	36.1%	7	8.4%	23	27.7%
30-39	20	24.1%	3	3.6%	17	20.5%
40-49	12	14.5%	3	3.6%	9	10.8%
50-59	10	12.0%	2	2.4%	8	9.6%
60+	2	2.4%	1	1.2%	1	1.2%

Table 8 show the frequency of participants by age group. As shown, the majority of respondents were aged between 18-39 years. All percentages shown are of the total number of participants (N=83).

9.1.3. The mean age of onset of SM will be before 4 years, based upon research on SM in children (H3)

As shown in Table 9, the mean age of onset is 3.78 in this study.

Table 9 — Key ages and SM

	N	**Min / max**	**Mean (SD)**	**Independent-samples gender comparison *t*-tests**
Age of onset	69	0 / 16	3.78 (4.47)	*t*(67)=-0.67, p=.50
Realization of difference	83	0 / 51	9.07 (9.18)	*t*(81)=-1.98, p=.19
Age of improvement / partial recovery	58	7 / 48	22.31 (8.26)	*t*(56)=0.57, p=.57
Age of recovery	4	17 / 40	24.50 (10.47)	-
Knew SM was named cond.	83	3 / 64	26.25 (13.43)	*t*(81)=-1.63, p=.11

Independent samples *t*-tests between genders (as shown in Table 9) reveal there to be no significant gender differences regarding age of onset, realization of difference, improvement / partial recovery, recovery or knowing SM was a named condition.

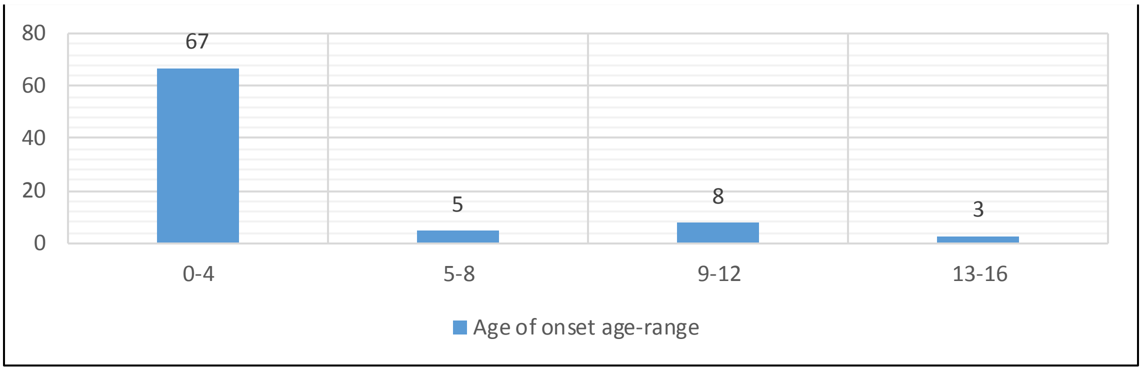


Figure 1 — Age of onset age-range frequencies

Figure 1 shows the frequencies of onset by groups of age-ranges. The majority of participants (80.7%) developed SM prior to age 4. A further 16 (19.3%) developed SM after age 4.

9.1.4. Most sufferers of SM will not have received a formal diagnosis (H4)

Table 10 shows the routes through which adults with SM discovered there was a name for their condition.

Table 10 — How adults with SM realized there was a name for their condition

Theme	**N**	**Percent**
I was diagnosed with SM as a child	20	26.3%
My child was diagnosed with SM and it described me also	6	7.9%
Internet research (self-diagnosis)	23	30.3%
TV documentaries (self-diagnosis)	19	25%
Books / magazines (self-diagnosis)	5	6.6%
Other research	3	3.9%
(Total)	76	(100%)

Of those who received a diagnosis in childhood, their current mean age was 24.2 (SD=7.38); of those without a diagnosis, their current mean age was 37.3 (SD=12.76). A *t*-test is significant: *t*(58.28)=5.54, p<.001*** (despite Levene's test being significant) – i.e. older participants are much more unlikely to have received a diagnosis.

Regarding this sample, adults in the UK and US are equally likely to have received a diagnosis of SM in childhood. The ratio of those having received a diagnosis in childhood versus those that did not is precisely 3:8 in both countries: in the UK, 12 received diagnoses and 32 did not; in the US, 6 received diagnoses and 16 did not.

Contrasting the reported severities of SM of those who received a diagnosis with those who did not indicates no significant *t*-test (see Table 11) which indicates that diagnosis was not followed up with effective therapeutic intervention or support.

Table 11 — *t*-test between reported severities of those who received a diagnosis of SM in childhood and those who did not

Age	Received diagnosis of SM in childhood	N	Mean SM severity (SD)	*t*-test
<5	No	42	3.88 (4.00)	*t*(55)=-0.39, p=.70
	Yes	15	4.33 (3.60)	
5-8	No	54	6.30 (3.28)	*t*(72)=1.21, p=.23
	Yes	20	5.30 (2.72)	
9-11	No	55	7.47 (2.49)	*t*(73)=1.91, p=.06
	Yes	20	6.30 (1.92)	
12-15	No	55	8.25 (1.96)	*t*(73)=0.20, p=.84
	Yes	20	8.15 (2.08)	
16-19	No	54	8.48 (1.58)	*t*(24.09)=1.47†, p=.15

	Yes	20	7.55 (2.67)	
20-24	No	52	7.54 (2.10)	*t*(63)=-0.72, p=.47
	Yes	13	8.00 (1.92)	
25-29	No	44	7.09 (2.11)	*t*(47)=0.69, p=.50
	Yes	5	6.40 (2.41)	
30-34	No	36	6.81 (2.64)	*t*(38)=-0.14, p=.88
	Yes	4	7.00 (2.16)	
35-39	No	28	5.93 (2.91)	*t*(28)=-0.03, p=.97
	Yes	2	6.00 (1.41)	
40-44	No	21	5.29 (2.39)	*t*(20)=-0.70, p=.49
	Yes	1	7.00	
45-49	No	15	5.47 (2.62)	*t*(14)=-1.31, p=.21
	Yes	1	9.00	
50-54	No	10	4.90 (2.81)	-
	Yes	1	-	
55-59	No	6	3.83 (3.66)	-
	Yes	0	-	

†Levene's statistic significant

9.1.5. There will be high levels of comorbidity in adults, particularly with other anxiety-related psychopathologies and eating disorders (H5)

Table 12 — Conditions comorbid with SM in childhood and adulthood

Condition	**As a child I had…**	**As an adult I have…**	**… and I feel that this condition stems from my childhood SM**	**… and I feel that this condition does not stem from my childhood SM**
Depression	24	44	32	12
Anxiety	26	43	34	11
An eating disorder	6	10	7	3

Panic disorder	12	12	10	2
Social anxiety	25	47	38	10
Agoraphobia	5	5	5	-
Separation anxiety	10	3	2	1
OCD	9	14	9	5
Post-traumatic stress	4	9	4	5
Other	4	16	9	8

Table 12 shows a list of self-reported comorbid conditions in childhood; and self-reported related and unrelated conditions in adulthood. Adults with SM tend to indicate that *many* adult conditions (not just social anxiety) stemmed from their childhood SM.

Other conditions identified via thematic analysis (Braun & Clarke, 2007) were: Asperger Syndrome, Body Dysmorphia, perfectionism generally allied with Body Dysmorphia (particularly around presentation and appearance), and suicidal feelings in childhood; and further to those: schizo-affective disorder, low self-esteem, paranoia, AvPD, self-harm, eating disorder, borderline personality disorder, bipolar disorder, and postnatal depression in adulthood. One participant strongly refutes a diagnosis of narcissistic personality disorder which was given because the participant could not speak.

The results of contrasting observed versus expected rates of mental health conditions for the general population using χ^2-tests, computed using the nonparametric χ^2-test legacy dialog in SPSS, are shown in Table 13 (see Appendix F for the scripts).

Table 13 — Rates of mental health conditions in adults with SM vs. the general population

	UK prevalence rate (Mental Health Foundation, 2007; Bebbington, et al., 2007)	**Expected frequency for an equally gender-biased population sample (how calculated)**	**Observed frequency who said "as an adult I have…"**	χ^2
Depression (Female, N=66)	11.64%	7.68 (.1164*66)	36	$\chi^2(1,N=66)=73.41$, p<.001***
Depression (Male, N=17)	10.29%	1.75 (.1029*17)	8	$\chi^2(1,N=17)=24.88$†, p<.001***
Anxiety (Female, N=66)	9.29%	6.13 (.0929*66)	35	$\chi^2(1,N=66)=111.23$, p<.001***
Anxiety (Male, N=17)	7.85%	1.33 (.0785*17)	8	$\chi^2(1,N=17)=31.38$†, p<.001***
Eating disorder (Female, N=66)	9.2%	6.07 (.092*66)	7	$\chi^2(1,N=66)=0.125$, p=.72
Eating disorder (Male, N=17)	3.5%	0.60 (.035*17)	3	$\chi^2(1,N=17)=31.38$†, p<.001***
Panic disorder (Female, N=66)	2.04%	1.35 (.0204*66)	10	$\chi^2(1,N=66)=9.951$†, p<.01**
Panic disorder (Male, N=17)	1.93%	0.33 (.0193*17)	2	$\chi^2(1,N=17)=8.62$†, p<.01**
Social anxiety (Both, N=83)	5%	4.15 (.05*83)	25	$\chi^2(1,N=83)=110.27$†, p<.001***
OCD (Both, N=83)	2.5%	2.08 (.025*83)	9	$\chi^2(1,N=83)=23.61$†, p<.001***
PTSD (Female, N=66)	3.3%	2.18 (.033*66)	8	$\chi^2(1,N=66)=16.07$†, p<.001***
PTSD (Male, N=17)	2.6%	0.44 (.026*17)	1	$\chi^2(1,N=17)=0.732$†, p=.39

†Cell with frequency less than 5, hence Fisher's exact test reported

Table 13 shows that those participants whose SM continues into adulthood are significantly more likely to develop other disorders in adulthood than the general population.

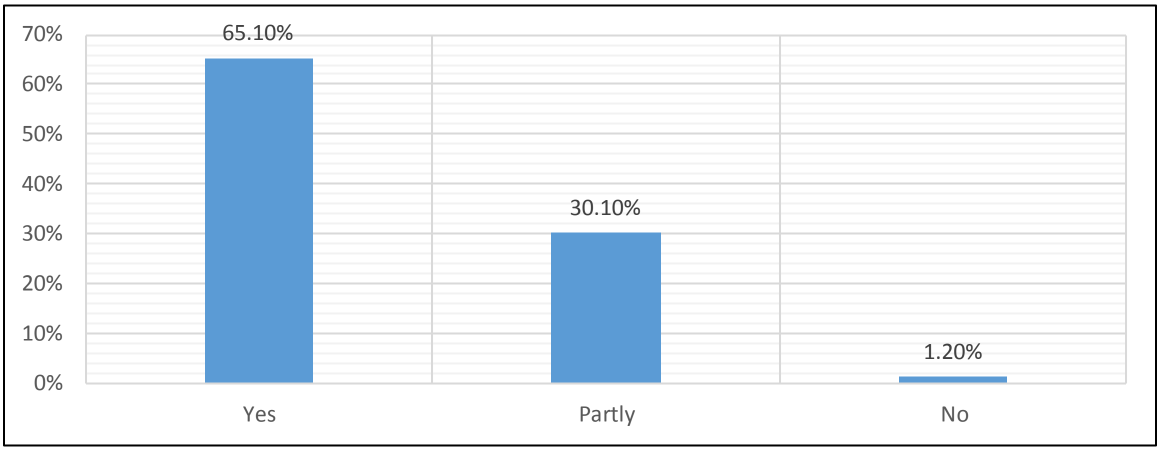


Figure 2 — Responses to whether outcomes related to SM could have been avoided

Asked whether adult outcomes related to SM (e.g. developing adult depression) could have been avoided, responses were given as shown in Figure 2.

As such, very few participants therefore felt that they could not have been helped in childhood to avoid conditions derived from or related to SM in adulthood. There were no gender or age-group related differences for these responses (analyses omitted for brevity).

Asked what could have helped in childhood, to avoid SM and related conditions in adulthood, participants gave the responses shown in Figure 3.

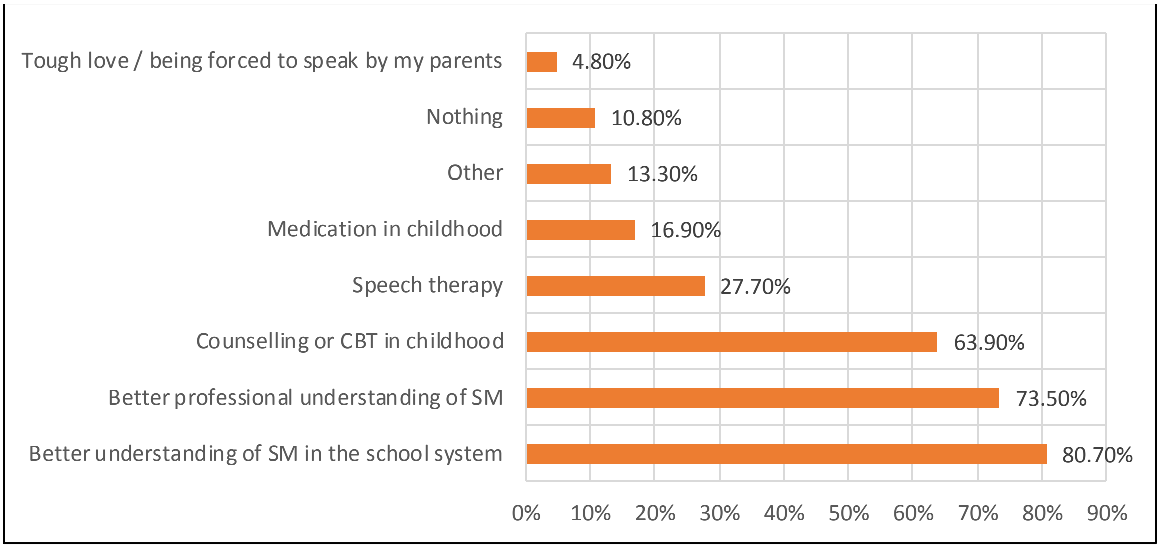


Figure 3 — Responses to "what could have helped in childhood?"

There were no significant age or gender differences in the responses given in Figure 3.

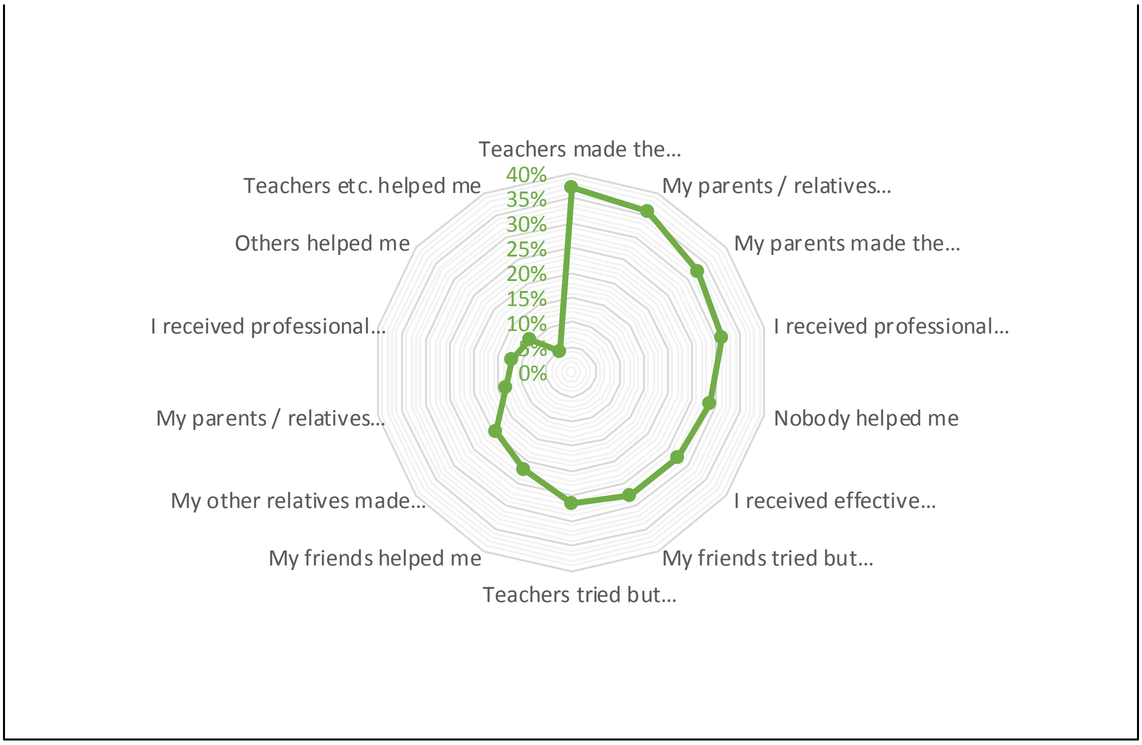


Figure 4 — Responses to "who helped you?"

Figure 4 shows responses to who helped with SM or made the problem worse. While some teachers tried to help (in 25% of cases), teachers on the whole were perceived to be those who were both most likely to make SM worse and to be the least helpful.

Table 14 — Age group differences regarding “who helped you?”

	Younger (N=51)	Older (N=32)	
Teachers etc. helped me	2	2	$\chi^2(1,N=83)=0.23$, p=.64
I received professional support which was detrimental	8	2	$\chi^2(1,N=83)=1.65$, p=.30
My parents / relatives helped me	10	1	$\chi^2(1,N=83)=4.65$, p=.04*
My other relatives made the problem worse	13	3	$\chi^2(1,N=83)=3.28$, p=.07
My friends helped me	13	5	$\chi^2(1,N=83)=1.13$, p=.29
Teachers tried to help me but they didn’t know how to, or weren’t able to	18	4	$\chi^2(1,N=83)=5.24$, p=.02*
My friends tried but weren’t able to help	18	5	$\chi^2(1,N=83)=3.80$, p=.05
I received effective professional support, which helped at least a little bit	14	9	$\chi^2(1,N=83)=0.00$, p=1.00
Nobody helped me	10	14	$\chi^2(1,N=83)=5.576$, p=.02*
I received professional support which was ineffective	19	7	$\chi^2(1,N=83)=2.16$, p=.14
My parents made the problem worse	16	11	$\chi^2(1,N=83)=0.08$, p=.78
My parents / relatives tried but weren’t able to help	22	8	$\chi^2(1,N=83)=2.80$, p=.09
Teachers made the problem worse	22	9	$\chi^2(1,N=83)=1.65$, p=.30

There were no gender differences between responses for “who helped you”. However there are differences if one contrasts younger and older participants (split on age=33.4) as given in Table 14: older participants were significantly less likely to be *successfully* helped by parents / relatives; significantly less likely to have found teachers who would have tried to help them; and significantly more likely to have received no help at all.

9.1.6. The severity of SM will slowly reduce with age (H6)

Participants were asked to self-rate the severity of their own SM from 0-10 (0 being no effect and 10 being severe) in every age range they have reached so far, leaving blanks when they (a) could not remember an age; or (b) had not reached it yet.

Table 15 shows that the peak of mean self-rated severity is between 12 and 19 years old.

Table 15 — Self-reported SM severity by age

	N	**Min/Max**	**Mean (SD)**	**One-sample *t*-test (with value 5.0)**	**Independent-samples gender *t*-tests**	**Ind.-samples younger v. older *t*-tests**
Age < 5	62	0 / 10	4.11 (3.95)	*t*(61)=-1.77, p=.08	*t*(60)=1.15, p=.25	*t*(60)=2.32, p=.02*
Age 5-8	81	0 / 10	6.02 (3.19)	*t*(80)=2.89, p<.01**	*t*(79)=1.44, p=.15	*t*(79)=1.76, p=.08
Age 9-11	82	0 / 10	7.11 (2.49)	*t*(81)=7.69, p<.001***	*t*(80)=1.53, p=.13	*t*(80)=0.88, p=.38
Age 12-15	82	0 / 10	8.12 (2.13)	*t*(81)=13.29, p<.001***	*t*(80)=0.65, p=.52	*t*(80)=0.99, p=.33
Age 16-19	81	2 / 10	8.20 (1.91)	*t*(80)=15.04, p<.001***	*t*(79)=0.76, p=.45	*t*(79)=1.55, p=.13
Age 20-24	71	2 / 10	7.54 (2.04)	*t*(70)=10.96, p<.001**	*t*(69)=0.22, p=.81	*t*(69)=-0.29, p=.78
Age 25-29	51	2 / 10	6.81 (2.11)	*t*(50)=7.05, p<.001***	*t*(49)=-0.57, p=.57	*t*(49)=-1.41, p=.16
Age 30-34	41	1 / 10	6.49 (2.54)	*t*(40)=4.55, p<.001***	*t*(39)=-0.55, p=.59	*t*(39)=-2.36, p=.02*
Age 35-39	30	1 / 10	5.56 (2.82)	*t*(29)=1.82, p=.08	*t*(28)=-0.87, p=.39	

Age 40-44	22	1 / 9	4.92 (2.36)	*t*(21)=2.89, p=.48	*t*(20)=-0.90, p=.38	
Age 45-49	16	0 / 9	5.06 (2.68)	*t*(15)=0.72, p=.32	*t*(14)=0.37, p=.72	
Age 50-54	10	0 / 8	4.08 (2.81)	*t*(9)=1.03, p=.91	*t*(8)=1.08, p=.31	
Age 55-59	6	0 / 10	3.29 (3.66)	*t*(5)=-0.78, p=.47	*t*(4)=0.51, p=.64	
Age 60+	2	2 / 3	1.25 (0.71)	*t*(1)=-5.00, p=.13		

Table 15 also includes a one-sample t-test against value 5.0 (i.e. half of the scale), which demonstrates that SM generally has a marked effect (in terms of how a participant feels SM affects them) between ages 5 and 34.

An independent-samples *t*-test for self-reported SM severity by gender demonstrates no significant differences. There are a couple of significant differences contrasting younger and older participants however: older participants indicating recalling a higher level of SM prior to age 5 (perhaps a result of recall bias) and a lower level of SM between 30 and 34.

9.1.7. SM is not limited to school / educational settings (H7)

Table 16 — Speech pattern distribution (situations in which muteness occurred)

	Mute with first-degree relatives	Mute with second-degree relatives	Mute with peers and the opposite sex	Mute with others
Age 10	20	47	55	67
Age 18	28	39	54	63
Now	17	28	27	44
Total	33	55	70	75

Table 16 shows the distribution of familial (first-degree) and social situations in which adults with SM could not speak and still cannot speak.

Figure 5 shows the frequency of specific situations in which muteness or significant reticence were experienced and still occur.

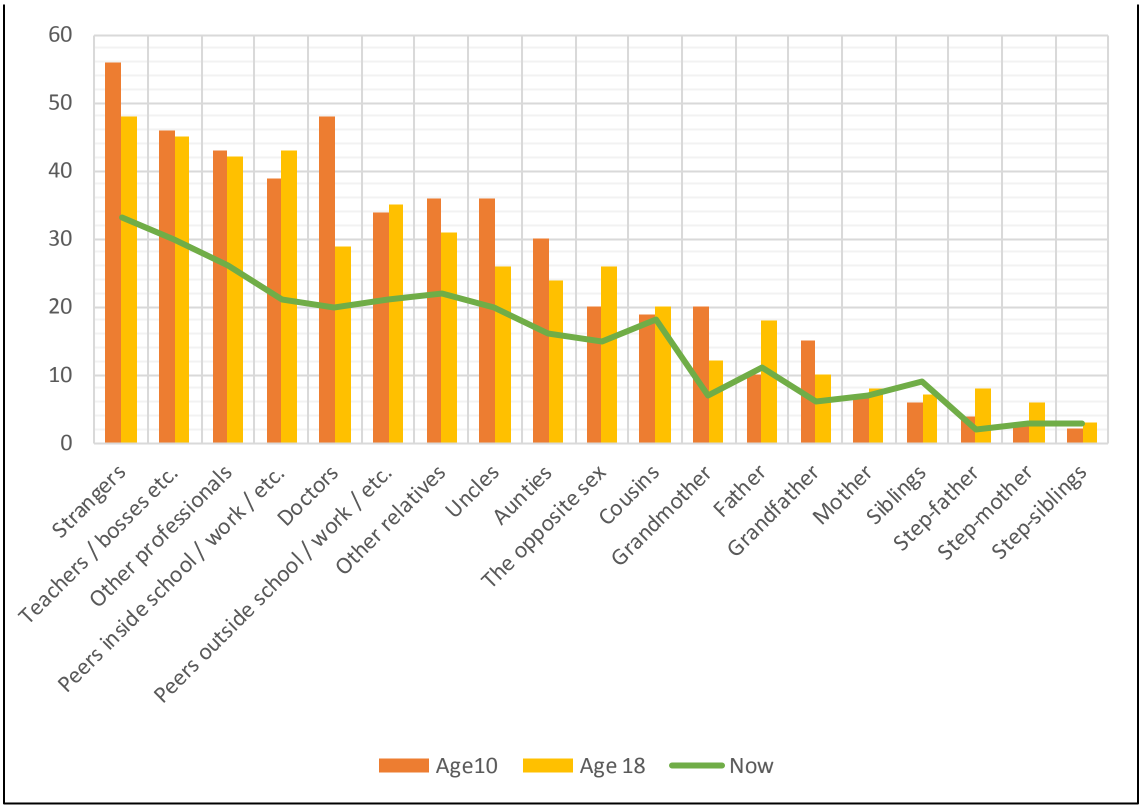


Figure 5 — Frequencies of speech inhibition by situation

It is still clear that SM remains a hindrance in any settings, not just "social" settings, for adults. Figure 5 also demonstrates a general decrease of severity / frequency of muteness in extra-familial situations between age 18 and 'now' for all participants.

As shown in Table 17, χ^2-tests indicate significant differences in speech pattern when one analyses speech patterns between ages 10 and 18 and between ages 18 and now (the duration in this case is variable per participant).

Table 17 — Changes in speech pattern between 10 to 18 and 18 until now

		Mute with first-degree relatives (at any age)	Mute with second-degree relatives (at any age)	Mute with peers and the opposite sex (at any age)	Mute with others (at any age)
Between 10 to 18	**$\chi^2(1,N=83)$** **p**	25.23 <.001***	19.36 <.001***	2.45 .12	11.20 <.01**
Between 18 until now	**$\chi^2(1,N=83)$** **p**	34.87 <.001***	1.57 .21	0.20 .66	2.16 .14

Table 18 shows the situations in which muteness occurred against age-permutation - i.e. whether muteness in a given situation occurred at three, two, or one of the ages per participant.

Table 18 — Settings in which muteness occurred vs. age permutations

Permutation	Mute with first-degree relatives	Mute with second-degree relatives	Mute with peers and the opposite sex	Mute with others
10, 18, and now	11	22	22	38
10 and 18	5	10	17	18
18 and now	5	4	4	4
10 only	4	14	15	10
18 only	7	3	11	3
Now only	1	1	0	1
10 and now	0	1	1	1
Total	33	55	70	75

Six participants indicated they were mute consistently in a situation at age 10, but were not at age 18 or now (indicated by†). As such they *may* have felt they were struggling to communicate at 18, but were not situationally mute any longer (or their mutism was erratic or unpredictable). Three other participants did not answer this set of questions.

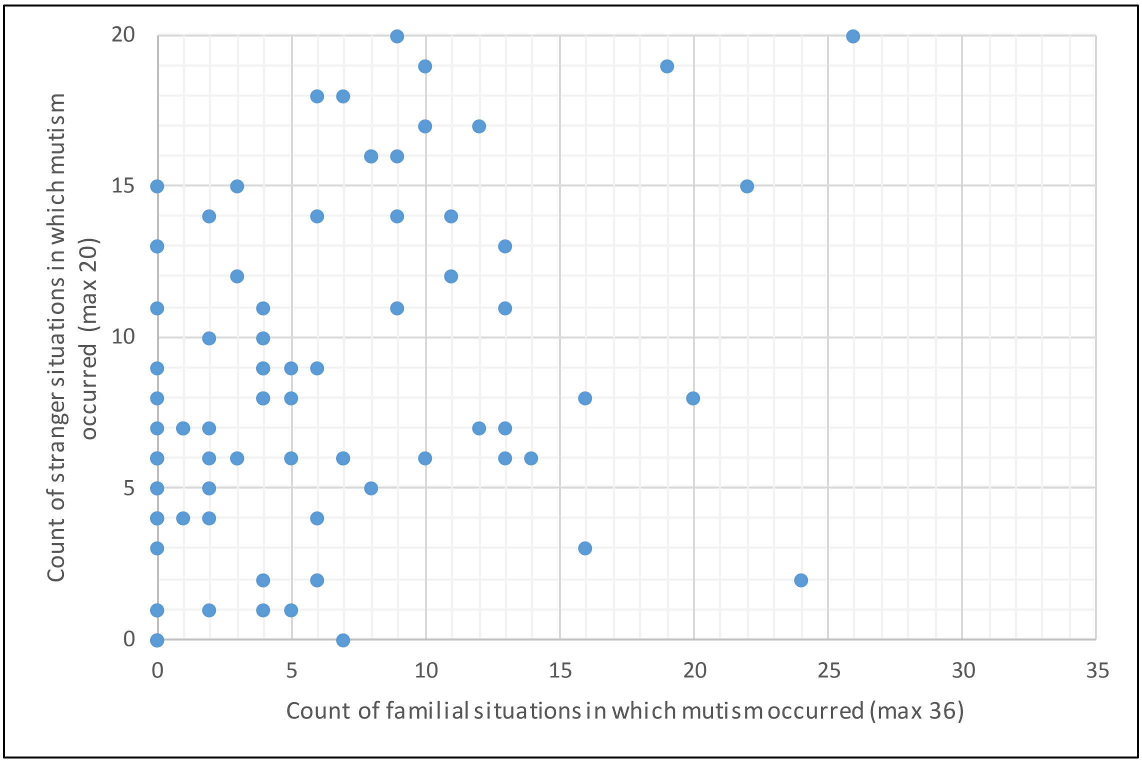


Figure 6 — Scatterplot between familial mutism (mutism with first and second degree relatives) and stranger mutism (mutism with peers and others)

Figure 6 shows a scatterplot of the total number (summing across all three ages) of familial 'situations' versus the total number of stranger 'situations' in which a participant was mute. Familial includes first and second-degree relatives; stranger includes peers and others. For further information regarding the computation of these axes, see Appendix E / Appendix F.

There is a significant correlation between the two axes: *r*(83)=0.37, p<.01**. While there a number of participants who were *only* mute with peers and others (N=21), who possibly form a distinct sub-group, the correlation indicates the relationship that those mute in more situations with peers and strangers are also more likely to be mute with familiars (first and second degree relatives) and vice versa. If one excludes those falling on the Y axis (those who were not mute with first or second degree relatives and only mute with peers and others) the correlation is still significant, but less so: *r*(60)=0.29, p=.02*.

Table 19 is table of χ^2-tests regarding how participants describe their own SM compared to the types of situation where they were mute, to indicate a few key differences in view and experience between those mute in different types of situation.

Table 19 — χ^2-tests of personal description of SM vs. situation

		Mute with first-degree relatives	**Mute with second-degree relatives**	**Mute with peers and the opposite sex**	**Mute with others**
SM is an illness	$\chi^2(1,N=83)$ **p**	0.87 .64	0.45 .66	0.99 1.00	0.57 1.00
SM is an autistic trait	$\chi^2(1,N=83)$ **p**	3.20 .11	0.09 1.00	0.96 .30	3.15 .13
SM is due to a sens. int. difficulty	$\chi^2(1,N=83)$ **p**	1.91 .26	0.06 1.00	0.07 1.00	2.40 .17
SM is a learned behaviour	$\chi^2(1,N=83)$ **p**	0.87 .35	6.70 .01*	0.14 .71	0.26 1.00
SM is a genetic difference	$\chi^2(1,N=83)$ **p**	0.18 .67	1.70 .19	1.00 .45	0.35 1.00
SM is an individual difference	$\chi^2(1,N=83)$ **p**	1.01 .32	0.37 .55	0.36 .72	0.06 1.00

SM is a specific phobia	**$\chi^2(1,N=83)$** **p**	0.09 .77	0.11 .74	0.00 1.00	0.54 .68
SM is a disability	**$\chi^2(1,N=83)$** **p**	0.86 .35	0.16 .69	1.17 .50	0.03 1.00
SM is an emotional problem	**$\chi^2(1,N=83)$** **p**	3.94 .05*	0.08 .77	1.59 .33	0.11 1.00
SM is a response to life experience	**$\chi^2(1,N=83)$** **p**	0.19 .67	0.18 .67	0.19 .76	0.48 .71
SM is a mental health problem	**$\chi^2(1,N=83)$** **p**	0.10 .75	0.49 .48	0.00 1.00	0.00 1.00
SM is an avoidant behaviour	**$\chi^2(1,N=83)$** **p**	0.11 .74	0.14 .70	0.00 .99	0.69 .48
SM is a response to my childhood family env.	**$\chi^2(1,N=83)$** **p**	5.91 .01*	1.78 .18	1.56 .21	0.49 .71
SM is the outcome of being a HSP	**$\chi^2(1,N=83)$** **p**	1.69 .19	0.30 .58	1.40 .24	3.95 .07
SM is a way of dealing with anx.	**$\chi^2(1,N=83)$** **p**	0.60 .44	1.38 .24	1.80 .18	1.15 .46
SM is an anxiety disorder	**$\chi^2(1,N=83)$** **p**	0.29 .59	0.74 .79	2.79 .12	1.05 .43
SM is a form of social phobia	**$\chi^2(1,N=83)$** **p**	0.86 .35	1.35 .25	2.62 .17	0.42 .68

*Significant at the 0.05 level ** Significant at the 0.01 level

There are only a few significant χ^2-tests shown in Table 19: those mute with first-degree relatives at some point in life are more likely to perceive SM as an emotional problem and a response to childhood family environment; and those mute in a second-degree relatives at some point in life are more likely to perceive SM as a learned behaviour.

9.1.8. SM is not a form of SAD, but is often comorbid with / develops into SAD (H8)

Figure 7 shows a chart indicating frequencies of descriptive terms participants chose to describe *their own* SM.

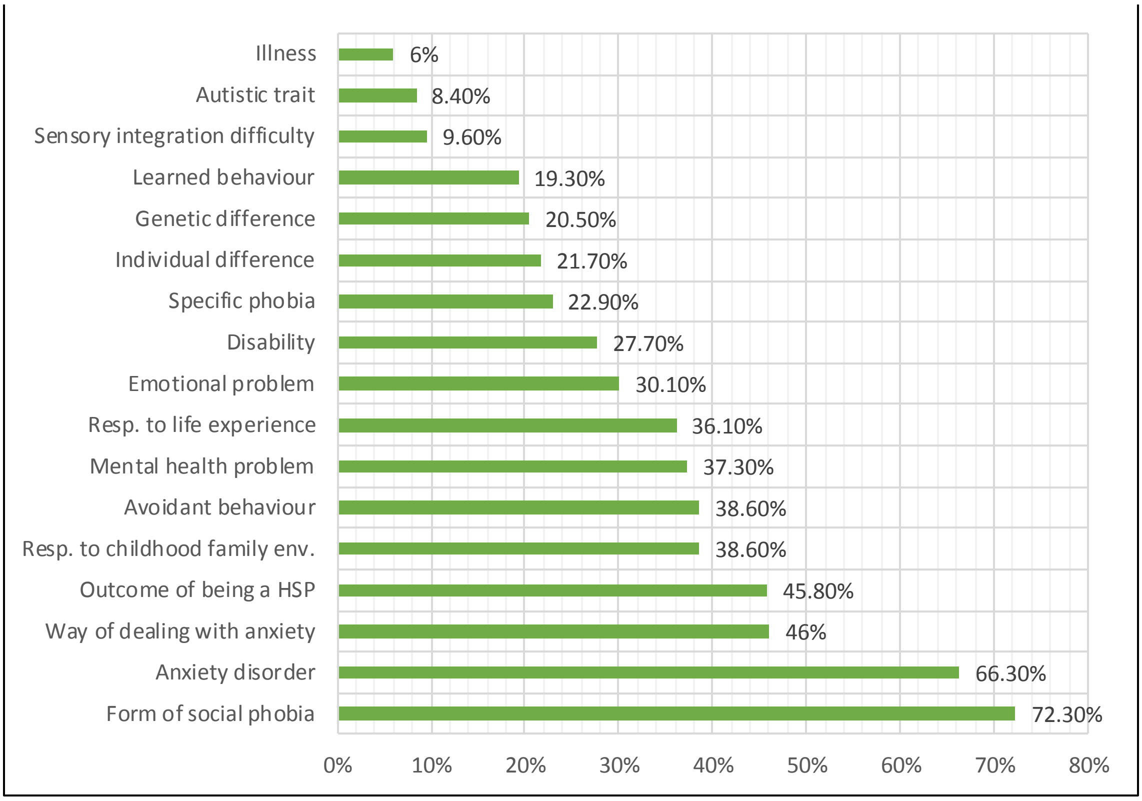


Figure 7 — How participants describe *their own* SM

It should be noted that while the majority of participants view SM to be a form of social phobia (when asked this simple yes / no question), a proportion (27.7%) do not feel that this is the case. This item (SM is a form of SP) is a key term which will be used throughout the results to perform statistical comparisons between those who believe SM to be a form and those who do not.

As shown in Table 20 a binary logistic regression indicates that those who believe SM to be a form of SP say so because they were likely to have experienced social phobia in childhood. Additional indicators are participants SM as an anxiety disorder and *not* having experienced post-traumatic stress disorder in childhood.

Table 20 — Hierarchical binary logistic regression evaluating predictors of participants saying SM is a form of SP

Factor	**B**	**SE**	**Sig**	**e^B**	**Cox & Snell R^2 (Nagelkerke R^2)**
Step 1					
SM is an anxiety disorder	1.53	0.53	<.01**	4.54	0.10 (0.14)
Step 2					
SM is an anxiety disorder	1.42	0.55	.01*	4.13	0.17 (0.24)
SM is a specific phobia	2.12	1.08	.05*	8.35	
Step 3					
SM is an anxiety disorder	1.66	0.61	<.01**	5.27	0.25 (0.36)
As a child I had social phobia	2.11	0.86	.01*	8.20	
SM is a specific phobia	2.20	1.12	.05*	8.95	
Step 4					

SM is an anxiety disorder	1.71	0.63	<.01**	5.51	0.30 (0.43)
As a child I had social phobia	2.79	1.12	.01*	16.32	
As a child I had post-traumatic stress disorder	-3.24	1.63	.05*	0.04	
SM is a specific phobia	2.05	1.13	.07	7.80	
Step 5					
SM is an anxiety disorder	1.81	0.67	<.01**	6.13	0.34 (0.49)
As a child I had social phobia	3.89	1.30	<.01**	48.65	
As a child I had anxiety	-1.79	0.85	.04*	0.17	
As a child I had post-traumatic stress disorder	-3.53	1.72	.04*	0.03	
SM is a specific phobia	2.28	1.26	.07	9.75	

As previously shown in Table 15, participants were asked to self-rate the severity of their SM within different ages. Hence participants gave up to 14 scores each, depending on how old they currently were, for the severity of their SM. In the second questionnaire, which participants were invited to complete only upon completing the first questionnaire and indicating they could be contacted again, participants were invited to self-rate the severity of their SP and shyness in the same way.

It is noteworthy, in light of Figure 20, that *every* person who completed the second questionnaire indicated some level of Social Phobia and shyness, even if minor.

Table 21 shows the mean self-reported severities of SM and SP at each age range.

Table 21 — Severities of SM and Social Phobia

Age	**SM**		**SP**	
	N	**Mean (SD)**	**N**	**Mean (SD)**
<5	62	4.11 (3.95)	36	4.89 (3.76)
5-8	81	6.02 (3.19)	47	6.26 (3.61)
9-11	82	7.11 (2.49)	51	6.53 (3.09)
12-15	82	8.12 (2.13)	52	7.48 (2.52)
16-19	81	8.20 (1.91)	52	7.67 (2.14)
20-24	71	7.54 (2.04)	47	7.17 (2.44)
25-29	51	6.81 (2.11)	37	6.95 (2.57)
30-34	41	6.49 (2.54)	30	6.13 (3.19)
35-39	30	5.56 (2.82)	23	5.74 (3.24)
40-44	22	4.92 (2.36)	18	5.06 (3.26)
45-49	16	5.06 (2.68)	16	5.13 (3.38)
50-54	10	4.08 (2.81)	11	4.73 (3.26)
55-59	6	3.29 (3.66)	8	3.13 (3.04)
60+	2	1.25 (0.71)	2	2.00 (0.00)

Performing paired-samples *t*-tests between SM and SP between those who say SM is a form of SP and those who do not yield the differences shown in Table 22.

The correlations between SM and SP severities are striking for those who said yes to “SM is a form of SP”. However, for those who did not say SM is a form of SP, there is no significant correlation within any age group.

Table 22 — Paired-samples *t*-tests and correlations between SM and Social Phobia between "SM is a form of SP" groups

Age	SM is a form of SP = 1		SM is a form of SP = 0	
	Correlation	*t*-test	Correlation	*t*-test
Age < 5	*r*(20)=0.61, p<.01**	*t*(21)=-2.78, p=.01*	*r*(9)=0.12, p=.73	*t*(10)=1.17, p=.27
Age 5-8	*r*(30)=0.60, p<.001***	*t*(31)=-2.28, p=.03*	*r*(12)=0.05, p=.87	*t*(13)=1.83, p=.09
Age 9-11	*r*(32)=0.72, p<.001***	*t*(33)=-1.25, p=.22	*r*(14)=0.36, p=.21	*t*(15)=2.07, p=.06
Age 12-15	*r*(33)=0.80, p<.001***	*t*(34)=0.82, p=.42	*r*(14)=0.39, p=.14	*t*(15)=2.10, p=.05
Age 16-19	*r*(33)=0.42, p=.01*	*t*(34)=0.00, p=1.00	*r*(14)=0.37, p=.16	*t*(15)=2.16, p=.05*
Age 20-24	*r*(29)=0.71, p<.001***	*t*(30)=0.67, p=.51	*r*(12)=0.07, p=.16	*t*(13)=1.13, p=.28
Age 25-29	*r*(22)=0.50, p=.01*	*t*(23)=-0.09, p=.93	*r*(9)=0.10, p=.77	*t*(10)=0.71, p=.50
Age 30-34	*r*(16)=0.55, p=.02*	*t*(17)=0.29, p=.78	*r*(7)=0.11, p=.78	*t*(8)=0.59, p=.57
Age 35-39	*r*(11)=0.73, p<.01**	*t*(12)=-0.26, p=.80	*r*(6)=0.32, p=.44	*t*(7)=0.72, p=.50
Age 40-44	*r*(7)=0.84, p<.01**	*t*(8)=-0.19, p=.86	*r*(5)=0.69, p=.09	*t*(6)=0.32, p=.76
Age 45-49	*r*(7)=0.88, p<.01**	*t*(8)=-0.63, p=.55,	*r*(2)=0.75, p=.25	*t*(3)=-0.23, p=.84
Age 50-54	*r*(5)=0.87, p=.01*	*t*(6)=-0.24, p=.82	-	*t*(1)=-3.00, p=.21
Age 55-59	*r*(3)=0.92, p=.03*	*t*(4)=0.89, p=.43	-	-
Age 60+	-	*t*(1)=1.00, p=.50	-	-

Evaluating further, and contrasting the difference between SP and SM for each participant: from Figure 8 it appears that for the group who do not indicate SM is a form of SP, their mean SM is persistently greater than their mean SP (although SP is still a factor) by a reducing amount which tends to about -1. In this case SP may be SM-led: i.e.

participants are socially anxious because they are aware they cannot speak (which may particularly become a factor after the age of realization of difference – see Table 9.)

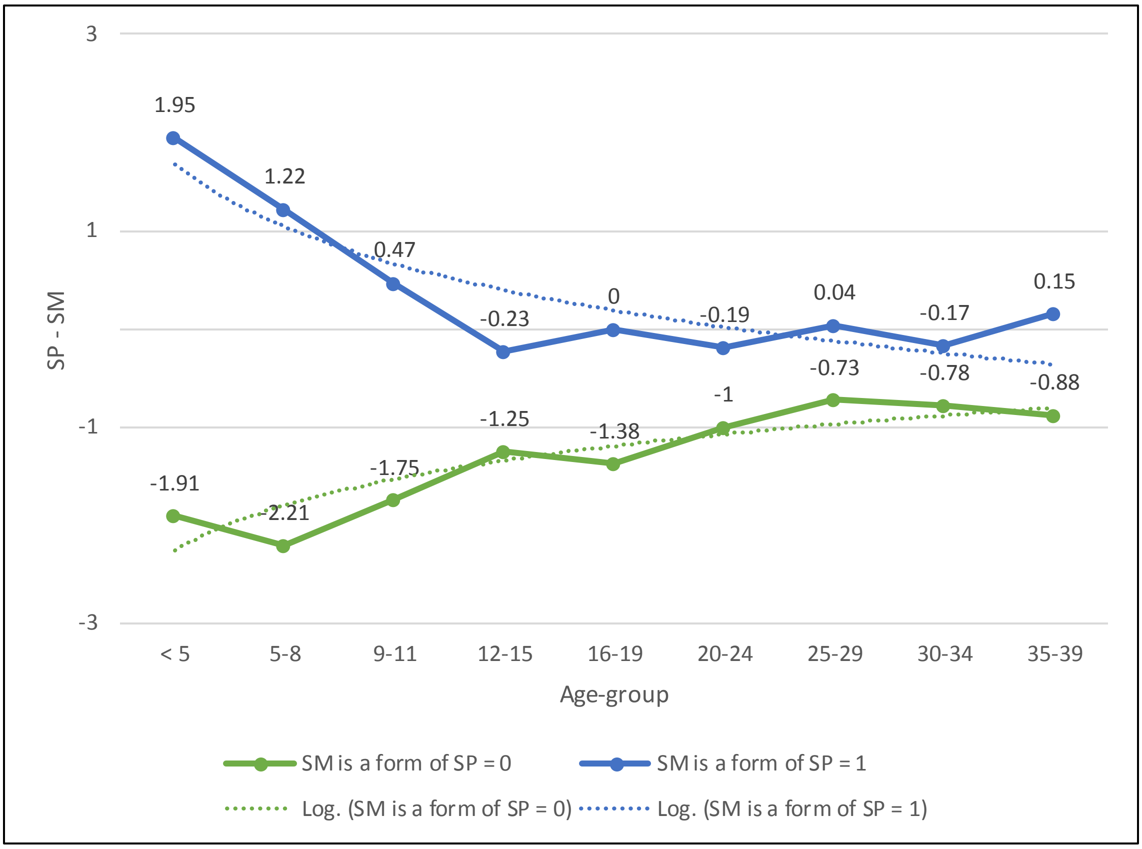


Figure 8 — Plot of SP-SM (difference between SP and SM) for those who said "SM is a form of SP" and those who did not

Both groups tend towards SP and SM severities being the same but neither group starts out that way. Figure 8 is a plot of SP-SM differences for each age group to 39, for both "SM is a form of SP" groups.

Independent-samples *t*-tests for SP-SM differences between the "SM is a form of SP" groups are significant up to age 12. Thus one can say that the two "SM is a form of SP" groups are statistically differentiable *up to age 12* as a more SP than SM group and a more SM than SP group.

Table 23 — Independent samples *t*-tests for SP-SM by age-group between those who said "SM is a form of SP" and those who did not

Age	SM is a form of SP	N	Mean (SD)	*t*-test
< 5	No	11	-1.91 (5.39)	*t*(31)=-2.56, p=.02*
	Yes	22	1.95 (3.30)	
5-8	No	14	-2.21 (4.53)	*t*(18.28)=-2.60†, p=.02* †Levene's statistic significant
	Yes	32	1.22 (3.02)	
9-11	No	16	-1.75 (3.38)	*t*(21.16)=-2.40†, p=.03* †Levene's statistic significant
	Yes	34	0.47 (2.19)	
12-15	No	16	-1.25 (2.38)	*t*(21.82)=-1.56†, p=.13 †Levene's statistic significant
	Yes	35	-0.23 (1.65)	
16-19	No	16	-1.38 (2.55)	*t*(24.94)=-1.88†, p=.07 †Levene's statistic significant
	Yes	35	0.00 (2.13)	
20-24	No	14	-1.00 (3.31)	*t*(15.82)=0.87†, p=.40 †Levene's statistic significant
	Yes	31	-0.19 (1.60)	
25-29	No	11	-0.73 (3.41)	*t*(13.88)=0.69†, p=.50 †Levene's statistic significant
	Yes	24	0.04 (2.18)	
30-34	No	9	-0.78 (3.93)	*t*(25)=-0.50, p=.62
	Yes	18	-0.17 (2.46)	
35-39	No	8	-0.88 (3.44)	*t*(19)=-0.85, p=.40
	Yes	13	0.15 (2.12)	
40-44	No	7	-0.29 (2.36)	*t*(14)=-0.39, p=.71
	Yes	9	0.11 (1.76)	
45-49	No	4	0.25 (2.22)	*t*(11)=-0.08, p=.94
	Yes	9	0.33 (1.58)	
50-54	No	2	1.50 (0.71)	*t*(7)=1.14, p=.29

	Yes	7	0.14 (1.57)	
55-59	No	1	2.00	$t(4)=1.57$, p=.19
	Yes	5	-0.60 (1.52)	

It is worth evaluating how variegated transitions between dominance of SM and SP are. Table 24 contrasts SP-SM at age range 5 to 8 with SP-SM at age range 20 to 24. The χ^2-test is not significant: $\chi^2(1,N=40)=3.18$, p=.09 (Fisher's exact test.)

Table 24 — Contrasting SP-SM at age range 5 to 8 with SP-SM at age range 20 to 24

	More SM than SP (age 20)	**More SP than SM (age 20)**	**Total**
More SM than SP (age 5)	7	5	12
More SP than SP (age 5)	8	20	28
Total	15	25	40

Table 25 contrasts those who experienced more SM than SP at any age with those who experienced more SP than SM at any age. Very few (N=4) consistently experienced SM at a higher rate than SP at all reported ages. Considerably more (N=15) consistently experienced SP at a higher rate than SM at *all* ages. Most (N=31) experienced a mixture of SP *and* SM being dominant at some time in their lives. Again, the χ^2-test is not significant: $\chi^2(1,N=50)=1.86$, p=.30 (Fisher's exact test.)

Table 25 — Contrasting SP-SM at all ages

		More SM than SP at any age		Total
		No	**Yes**	
More SP than SM at any age	**No**	N/A	4	4
	Yes	15	31	46
	Total	15	35	50

9.1.9. SM is the result of a G x E interaction, hence is partly genetic (H9)

From the text data (see Appendix H), seven mums of children with SM took part in this research whose own SM extended into adulthood. One child was of adult age and *also* took part. The mums with SM had, between them, 6 female children and 1 male child with SM.

Figure 9 shows the number and percentages of participants who said there was a contributing trigger or environmental factor for their SM. As many participants experienced triggers as those who definitely did not (≈40% in both cases.)

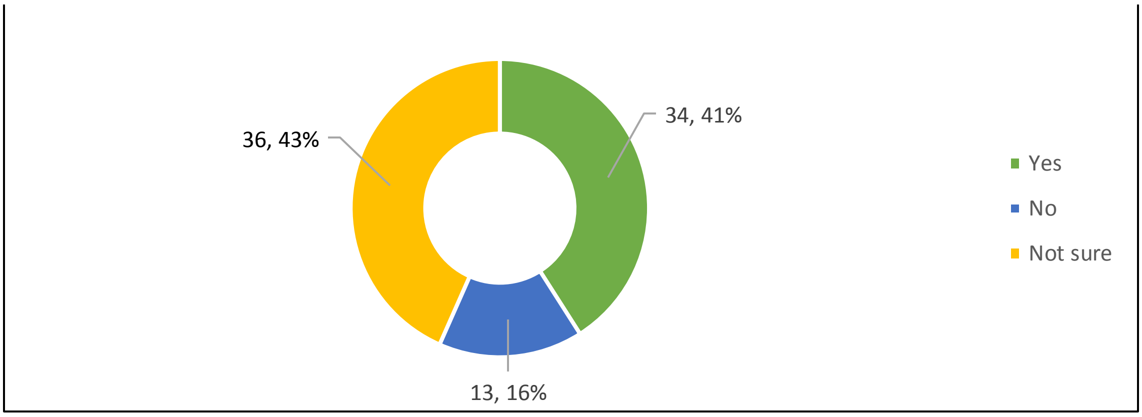


Figure 9 — Triggers and environmental factors and SM

Asked about triggers and environmental factors involved in forming and/or maintaining SM to and beyond age 18, themes of abuse within the childhood home emerged for a significant minority (≈22%) of the participants, shown in Table 26.

Bullying was the primary kind of abuse outside the home (see Figure 13 on page 88.). Additionally there were also two participants who implicated sexual assault as a contributing factor for their SM; and one participant expressly cited a teacher as the main source of emotional abuse.

Table 26 — Experiences of abuse in relation to SM (themes)

Experienced abuse within the home environment		
	N	**Percent**
Witnessed domestic violence	4	4.8%
Abusive family environment (not specified)	5	6.0%
Abusive father (usually emotionally, sometimes physically)	7	8.4%
Abusive mother (emotionally and physically)	1	1.2%
Abusive stepfather (emotionally, sometimes physically)	2	2.4%
Experienced some form of abuse within the home, and ascribe this to causing or contributing to SM (Total)	18	21.7%
Experienced abuse outside the home environment		
	N	**Percent**
Bullying (not within the home environment)	23-34‡	27.7%-41.0%
Abusive teacher (emotionally)	1	1.2%
Sexual assault (not within the home environment)	2	2.4%
Experienced some form of abuse outside the home, and ascribe this to causing or contributing to SM (Total)	24-35‡	28.9%-42.2%

‡This uncertainty is because 11 of those who experienced abuse within the home also expressed that they were mute because they were bullied. Thus for 11 the bullying may or may not have been within the home environment.

Those who experienced abuse and SM within the home environment were more likely to report anxiety, an eating disorder, social phobia, and post-traumatic stress disorder in adulthood than the rest of the sample, as shown in Table 27.

Table 27 — Adult and child mental health conditions and SM for those who experienced abuse within the home environment compared to those who did not

	Childhood mental health conditions (comorbid with SM)	**Adult mental health conditions (comorbid with SM)**
Depression	$\chi^2(1,N{=}80)=3.81$, $p=.07$†	$\chi^2(1,N{=}83)=3.41$, $p=.07$
Anxiety	$\chi^2(1,N{=}80)=1.15$, $p=.28$	$\chi^2(1,N{=}83)=3.84$, $p=.05$*
An eating disorder	$\chi^2(1,N{=}80)=3.65$, $p=.09$†	$\chi^2(1,N{=}83)=5.37$, $p=.04$*†
Panic disorder	$\chi^2(1,N{=}80)=0.10$, $p=1.00$†	$\chi^2(1,N{=}83)=1.12$, $p=.28$†
Social anxiety	$\chi^2(1,N{=}80)=3.27$, $p=.07$	$\chi^2(1,N{=}83)=4.19$, $p=.04$*
Agoraphobia	$\chi^2(1,N{=}80)=1.33$, $p=.26$†	$\chi^2(1,N{=}83)=0.01$, $p=1.00$†
Separation anxiety	$\chi^2(1,N{=}80)=2.86$, $p=.11$†	$\chi^2(1,N{=}83)=0.25$, $p=.53$†
OCD	$\chi^2(1,N{=}80)=0.03$, $p=1.00$†	$\chi^2(1,N{=}83)=0.47$, $p=.49$†
Post-traumatic stress disorder	$\chi^2(1,N{=}80)=16.84$, $p<.01$**†	$\chi^2(1,N{=}83)=12.03$, $p<.01$**

†Cell with frequency less than 5, hence Fisher's exact test reported

Likewise, participants who experienced abuse and SM within their childhood home were more likely to report post-traumatic stress disorder in childhood.

Those who experienced abuse - either within the home or outside - expressed their experience of SM in the same way as those that did not: for descriptions of SM given in

Table 45, no χ^2-test yielded a significant difference between those that experienced abuse and those that did not.

However, those who experienced abuse at home were more likely to say SM was a response to childhood family environment and life experience: $\chi^2(1,N=83)=4.94$, p=.03* and $\chi^2(1,N=83)=6.20$, p=.01* respectively. Additionally however, those who experienced abuse within the home were also more likely to say that SM is a *genetic difference*: $\chi^2(1,N=83)=4.78$, p=.05* (Fisher's exact test). They did *not* describe their SM differently regarding any other term given in Table 19. Of those who experienced some form of abuse within the childhood home, a difference in speech pattern was apparent, shown in Table 28.

Table 28 — Speech pattern and abuse

		Mute with first-degree relatives	**Mute with second-degree relatives**	**Mute with peers and the opposite sex**	**Mute with others**
Experienced abuse within the home (N=18)	**$\chi^2(1,N=83)$** **Sig**	4.38 .04*	<0.01 .97	2.56 .14†	2.45 .19†
Experienced abuse within the home *and* experienced bullying (N=12)	**$\chi^2(1,N=83)$** **Sig**	7.27 .01**	0.48 .74†	0.01 .92†	1.50 .60†
Experienced abuse outside the home (including bullying) but did not experience abuse within the home (N=23)	**$\chi^2(1,N=83)$** **Sig**	0.18 .67	0.16 .69	1.17 .50†	3.39 .10†

†Cell with frequency less than 5, hence Fisher's exact test reported

Those who experienced abuse at home were more likely to be mute with first-degree relatives (even more so if bullying was involved either within the home or at school), but were not more likely to be selectively mute in other situations.

A binary logistic regression (shown in Table 29) indicates that those mute at 18 with first-order relatives experienced abuse at home *or* felt that SM was *an autistic trait*.

At maximum, Cox and Snell R^2 is .44 for the considered terms. The primary predictor of being mute with first-order relatives at age 18 is being mute with first-order relatives at age 10.

Table 29 — Hierarchical binary logistic regression evaluating predictors of muteness with first-order relatives at age 18

Factor	**B**	**SE**	**Sig**	**e^B**	**Cox & Snell R^2 (Nagelkerke R^2)**
Step 1					
Mute with first-order relatives at age 10	2.83	0.65	<.001***	17.00	.26 (.36)
Step 2					
Mute with first-order relatives at age 10	2.95	0.68	<.001***	19.07	.32 (.44)
Experienced abuse in the home environment	1.69	0.67	.01*	5.41	
Step 3					
Mute with first-order relatives at age 10	3.15	0.73	<.001***	23.40	.35 (.48)

Experienced abuse in the home environment	1.90	0.72	<.01**	6.67	
SM is an "autistic trait"	2.19	1.09	.04*	8.95	
Step 4					
Mute with first-order relatives at age 10	3.62	0.87	<.001***	37.29	.41 (.56)
Experienced abuse in the home environment	2.06	0.83	.01*	7.84	
SM is an "autistic trait"	3.06	1.21	.01*	21.29	
SM is an emotional problem	2.01	0.76	<.01**	7.43	
Step 5					
Mute with first-order relatives at age 10	3.78	0.92	<.001***	43.71	.44 (.61)
Experienced abuse in the home environment	1.79	0.88	.04*	5.96	
SM is an "autistic trait"	2.95	1.28	.02*	19.03	
SM is an emotional problem	1.86	0.78	.02*	6.42	
SM is a response to my childhood family environment	1.51	0.70	.03*	4.53	

Table 30 below shows that those who experienced abuse within their childhood home were more likely to experience SM unremittingly into their 50s. Divergence was significant from age 35 onwards as shown graphically in Figure 10.

Table 30 — SM severity and abuse within the home

	Did not experience abuse within the childhood home		Experienced abuse within the childhood home		*t*-test
	N	Mean (SD)	N	Mean (SD)	
Age < 5	47	3.83 (3.78)	15	5.00 (4.44)	*t*(60)=-1.00, p=.32
Age 5-8	63	5.90 (3.20)	18	6.44 (3.22)	*t*(79)=-0.63, p=.53
Age 9-11	64	6.97 (2.56)	18	7.61 (2.20)	*t*(80)=-0.97, p=.34
Age 12-15	64	8.17 (7.94)	18	7.94 (2.04)	*t*(80)=0.40, p=.69
Age 16-19	63	8.25 (1.80)	18	8.00 (2.33)	*t*(79)=0.49, p=.62
Age 20-24	56	7.73 (2.00)	15	7.33 (2.23)	*t*(69)=0.67, p=.50
Age 25-29	39	6.82 (2.05)	12	7.92 (2.15)	*t*(49)=-1.60, p=.12
Age 30-34	31	6.42 (2.58)	10	8.00 (2.11)	*t*(39)=-1.75, p=.09
Age 35-39	21	5.10 (2.66)	9	7.89 (2.20)	*t*(28)=-2.76, p=.01**
Age 40-44	15	4.60 (2.17)	7	7.00 (2.00)	*t*(20)=-2.48, p=.02*
Age 45-49	10	4.70 (2.95)	6	7.33 (0.82)	*t*(11.12)=-2.63†, p=.02*
Age 50-54	7	3.71 (2.50)	3	7.67 (0.58)	*t*(8)=-2.63, p=.030*
Age 55-59	5	2.60 (2.30)	1	10.0	*t*(4)=-2.93, p=.043*
Age 60+	2	2.50 (0.71)	0	-	-

†Levene's statistic significant

Those who did not experience such abuse were more likely to recover almost entirely by their late 50s. This includes those who experienced abuse outside the home "only" (through bullying etc.) who followed the gradual, general trend of improvement.

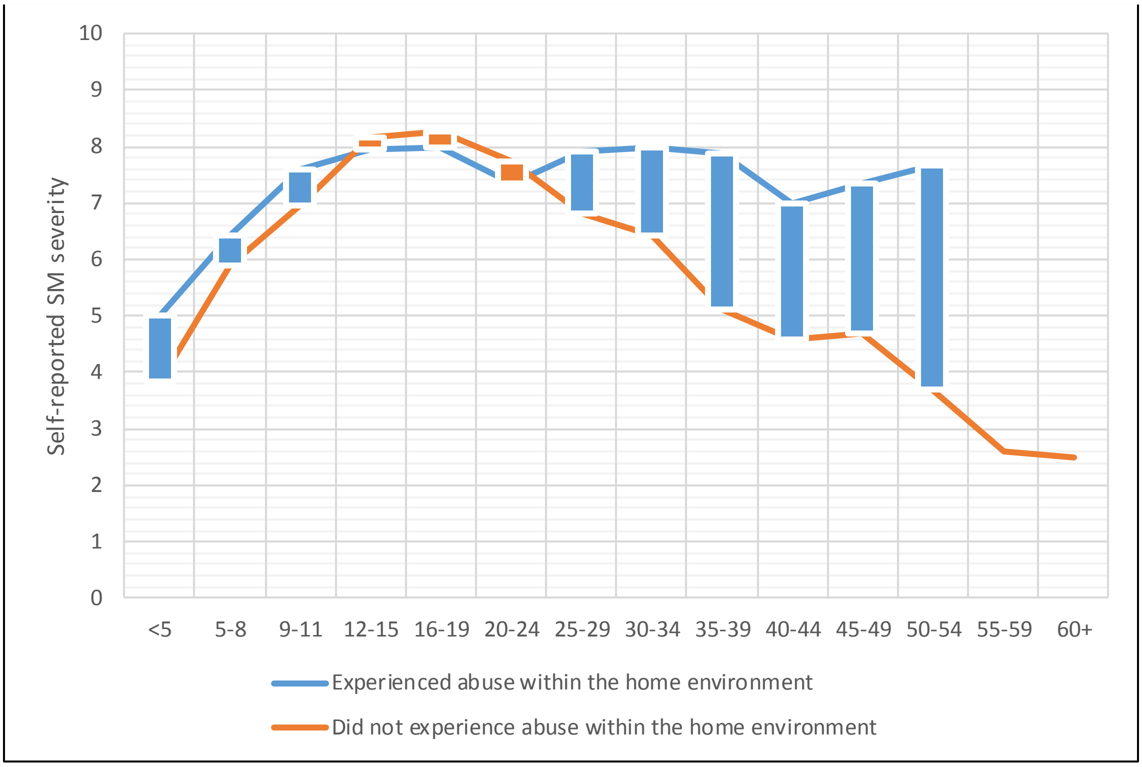


Figure 10 — SM severity and abuse within the home

9.1.10. SM in adults is not limited to western cultures (i.e. is worldwide, unlike Anorexia Nervosa) (H10)

As shown in Figure 11, there was participation in this study from 11 countries. The responses are UK-centric because the research was primarily advertised through UK-based support group: http://www.iSpeak.org.uk. Many US responses were collected due to the study being advertised on http://www.SelectiveMutism.org also.

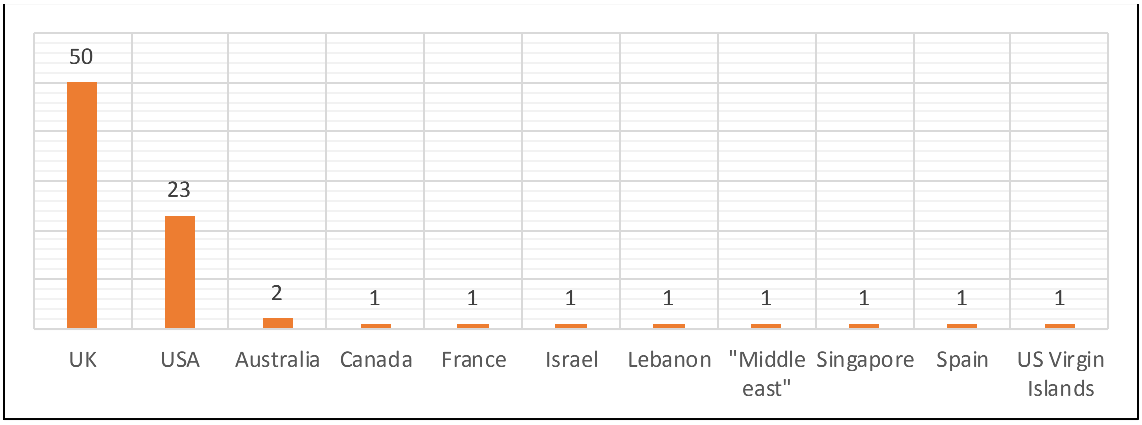


Figure 11 — Participation by country

9.2. Phenomological findings, not related to the hypotheses

Investigating how participants feel about SM, and the broad effects SM had on their lives, participants were asked to answer a number of likert scale questions as shown in Figure 12. The data collected were normalized to a scale of -1 to 1.

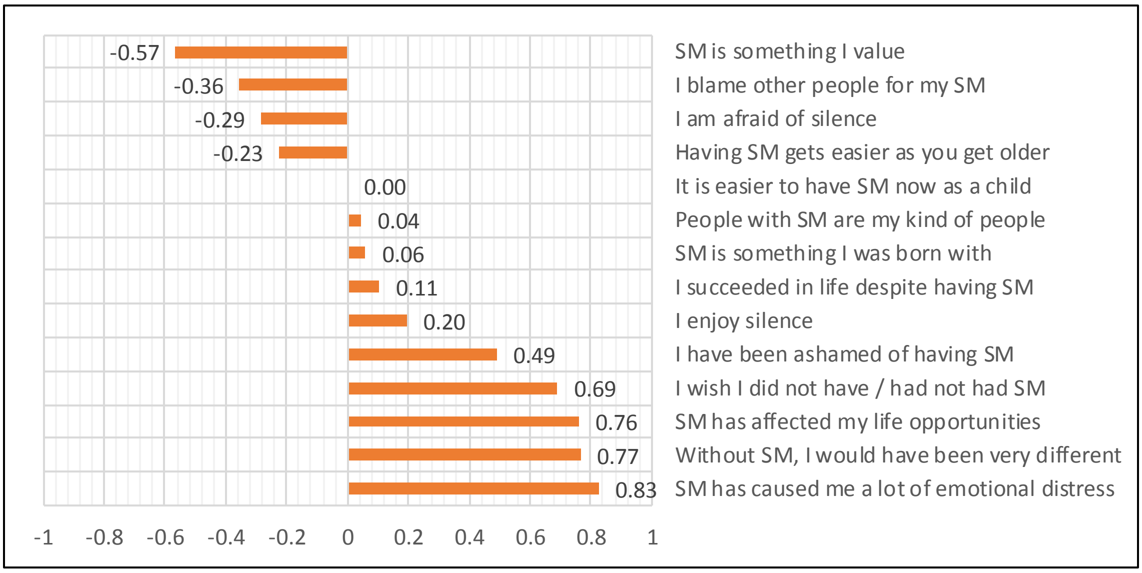


Figure 12 — What participants felt about SM

Contrasting younger and older, male and female participants regarding what they feel about SM the descriptive statistics are given in Table 31. The ANOVA results are given in Table 32.

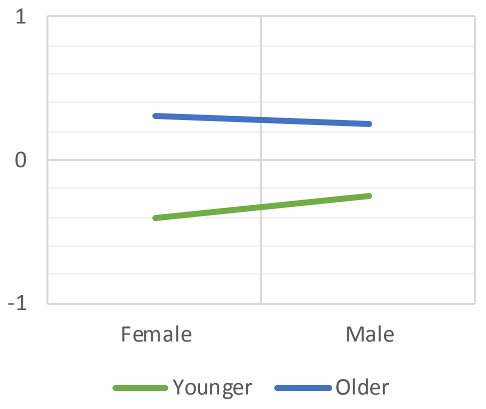
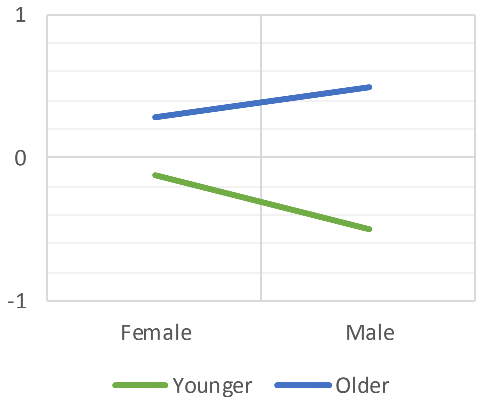
Table 31 — Descriptive stats for ANOVA of ratings vs. gender and ratings vs. age category

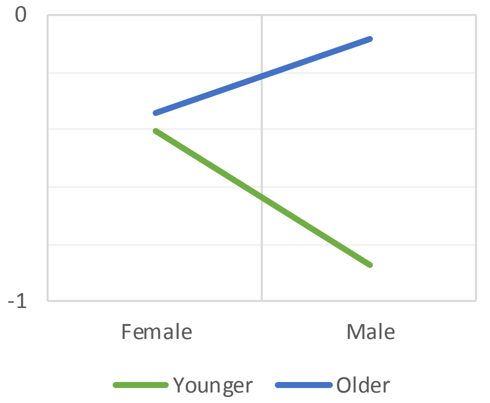
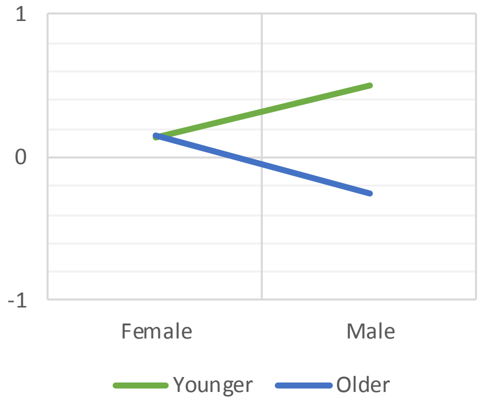
	Female		**Male**	
	Older (N=16)	**Younger (N=21)**	**Older (N=6)**	**Younger (N=4)**
	Mean (SD)	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**
SM is something I value	-0.56 (0.48)	-0.52 (0.54)	-0.75 (0.42)	-0.50 (0.58)
I blame other people for my SM	-0.34 (0.53)	-0.40 (0.52)	-0.08 (0.80)	-0.87 (0.25)
I am afraid of silence	-0.41 (0.46)	-0.29 (0.44)	-0.33 (0.75)	-0.38 (0.25)
Having SM gets easier as you get older	0.03 (0.64)	-0.40 (0.51)	0.25 (0.52)	-0.25 (0.87)
It is easier to have SM now compared to when I was a child	0.28 (0.58)	-0.12 (0.63)	0.50 (0.32)	-0.50 (0.58)
People with SM are my kind of people	0.16 (0.51)	0.14 (0.39)	-0.25 (0.52)	0.50 (0.41)
SM is something I was born with	0.63 (0.70)	0.14 (0.57)	0.25 (0.69)	-0.13 (0.48)
I succeeded in life despite having SM	0.22 (0.68)	0.02 (0.66)	0.25 (0.69)	-0.13 (0.48)
I enjoy silence	0.16 (0.54)	0.12 (0.65)	0.33 (0.61)	0.63 (0.25)
I have been ashamed of having SM, which made it even worse	0.41 (0.61)	0.38 (0.76)	0.42 (0.80)	-0.25 (0.87)
I wish I did not have / had not had SM	0.72 (0.41)	0.62 (0.55)	0.75 (0.42)	0.75 (0.29)
SM has affected my life opportunities	0.75 (0.26)	0.81 (0.37)	1.00 (0.00)	0.88 (0.25)

Without SM, I would have been very different	0.78 (0.31)	0.79 (0.34)	0.75 (0.27)	0.88 (0.25)
SM has caused me a lot of emotional distress	0.72 (0.52)	0.81 (0.29)	0.92 (0.20)	0.62 (0.48)

The ANOVA yield a few significant results shown in Table 32 - none attributable to gender alone. Those results which were not significant are omitted for the sake of brevity.

Table 32 — ANOVA of ratings vs. gender and age category

Having SM gets easier as you get older	The main effect of age category is significant: F(1,46)=4.72, p=.04* The main effect of gender is not significant: F(1,46)=0.15, p=.70 The interaction between age category and gender is not significant: F(1,46)=0.02, p=.88	
It is easier to have SM now as a child compared to when I was a child	The main effect of age category is significant: F(1,46)=11.09, p<.01** The main effect of gender is not significant: F(1,46)=0.15, p=.70 The interaction between age category and gender is not significant: F(1,46)=2.03, p=.16	

I blame other people for my SM	The main effect of age category is significant: F(1,46)=4.54, p=.04* The main effect of gender is not significant: F(1,46)=0.28, p=.60 The interaction between age category and gender is not significant: F(1,46)=3.34, p=.08	
People with SM are my kind of people	The main effect of age group is significant: F(1,46)=5.03, p=.03* The main effect of gender is not significant: F(1,46)=0.02, p=.88 The interaction between age category and gender is significant: F(1,46)=5.40, p=.03*	

The results in Table 32 show that older participants were more likely to say SM gets easier as one gets older; older participants were more likely to say it is easier to have SM now as a child; older participants were more likely to blame others - however *blame* is generally not apportioned anyhow (the means are negative); and older males are significantly less likely to say people with SM are their kind of people – i.e. are less likely to have affinity with others in the same situation.

NB: Levene's test of equality of error variances is significant for "SM has affected my life opportunities". This term does not yield a significant main effect of age or gender, or a significant interaction, so it is safe to note but ignore the Levene's test result in this instance.

t-tests for "having SM gets easier as you get older" and "I blame other people for my SM" (normalized items also shown in Table 31) are significant when contrasting those who experienced abuse within the childhood home environment with those that did not: see Table 33.

Table 33 — Feelings about SM and abuse

	Did not experience abuse within the home environment		**Experienced abuse within the home environment**		***t*-tests**
	N	**Mean (SD)**	**N**	**Mean (SD)**	
SM is something I value	60	-0.57 (0.56)	17	-0.56 (0.53)	*t*(64)=0.86, p=.40
I blame other people for my SM	58	-0.45 (0.53)	18	-0.06 (0.56)	*t*(74)=-2.71, p<.01**
I am afraid of silence	62	-0.33 (0.51)	18	-0.14 (0.64)	*t*(78)=.66, p=.51
Having SM gets easier as you get older	61	-0.15 (0.60)	16	-0.53 (0.46)	*t*(75)=2.37, p=.02*
It is easier to have SM now compared to when I was a child	46	-0.01 (0.60)	14	0.36 (0.75)	*t*(58)=-0.24, p=.81
People with SM are my kind of people	50	0.04 (0.51)	15	0.07 (0.37)	*t*(63)=-0.19 p=.85
SM is something I was born with	50	0.10 (0.64)	16	-0.06 (0.73)	*t*(64)=0.86, p=.40
I succeeded in life despite having SM	60	0.11 (0.63)	17	0.09 (0.67)	*t*(75)=0.11, p=.91
I enjoy silence	62	0.22 (0.56)	18	0.11 (0.76)	*t*(22.55)=.56, p=.58

I have been ashamed of having SM, which made it even worse	62	0.43 (0.66)	18	0.69 (0.54)	*t*(78)=-1.56, p=.12
I wish I did not have / had not had SM	61	0.72 (0.32)	18	0.75 (0.39)	*t*(74)=0.42, p=.68
SM has affected my life opportunities	61	0.76 (0.32)	18	0.75 (0.39)	*t*(77)=0.14, p=.89
Without SM, I would have been very different	57	0.76 (0.31)	17	0.76 (0.31)	*t*(72)=-0.18 p=.91
SM has caused me a lot of emotional distress	62	0.81 (0.35)	18	0.86 (0.23)	*t*(78)=-0.53, p=.60

†Levene's statistic significant

Those who experienced abuse within the home environment were less likely to say SM gets easier (in support of the results shown in Table 30).

They were not, however, less likely to say that SM is something they were born with; or significantly more likely to say that SM has caused them distress or to wish they did not have SM (the distress of having SM is almost universal.)

While those who experienced abuse within the home environment were more likely to ascribe blame, it should still be noted that very often such participants were forgiving / magnanimous: the mean for this group for this item was still marginally negative.

The three main "reasons" for mutism are: shyness, suggesting that SM is an inveterate psychophysiological response or trait; a high degree of inexplicability, suggesting that either SM is a subconscious response or, if SM is a conditioned response, conditioning generally occurred prior to the boundary of ordinary childhood amnesia (Davis, Gross, &

Hayne, 2008); and fear of “what other’s thought about me”, which is indicative of social anxiety.

Of the choices given, Figure 13 indicates the “reasons” for muteness chosen by all participants. Participants were able to tick as many “reasons” as were applicable.

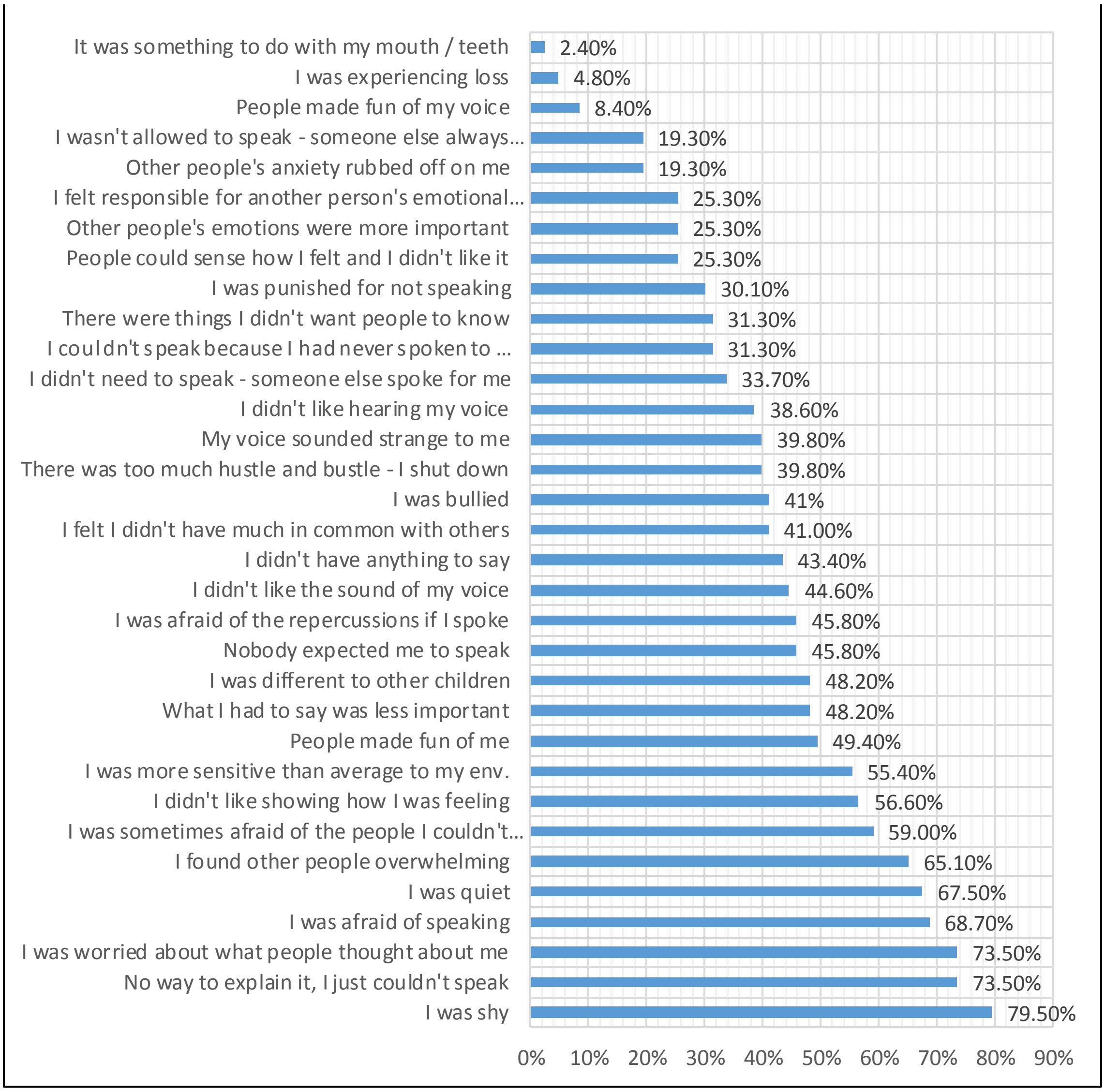


Figure 13 — Reasons chosen (from those given) for mutism at any stage of the condition

χ^2-tests identify gender and age-group related differences for these choices, as shown in Table 34.

Table 34 — Age and gender differences regarding reasons for mutism

Reason		**Younger (N=51) vs. older (N=32)**	**Female (N=66) vs. male (N=17)**
It was something to do with my mouth or teeth	**$\chi^2(1,N=83)$** **Sig**	0.11 1.00†	0.53 1.00†
I was experiencing loss	**$\chi^2(1,N=83)$** **Sig**	0.33 1.00†	0.05 1.00†
People made fun of my voice	**$\chi^2(1,N=83)$** **Sig**	1.12 .42†	1.97 .34†
I wasn't allowed to speak – someone else always spoke for me	**$\chi^2(1,N=83)$** **Sig**	0.23 .64	0.25 .73†
Other people's anxiety rubbed off on me	**$\chi^2(1,N=83)$** **Sig**	0.01 .92	1.41 .30
I felt responsible for another person's emotional welfare	**$\chi^2(1,N=83)$** **Sig**	0.98 .32	0.04 1.00†
Other people's emotions were more important	**$\chi^2(1,N=83)$** **Sig**	0.22 .64	0.04 1.00†
People could sense how I felt and I didn't like it	**$\chi^2(1,N=83)$** **Sig**	<0.01 .96	0.19 .76†
I was punished for not speaking	**$\chi^2(1,N=83)$** **Sig**	2.73 .10	<0.01 .94
There were things I didn't want people to know	**$\chi^2(1,N=83)$** **Sig**	0.25 .62	1.86 .17
I couldn't speak because I had never spoken to …	**$\chi^2(1,N=83)$** **Sig**	2.16 .14	0.96 .33
I didn't need to speak – someone else always spoke for me	**$\chi^2(1,N=83)$** **Sig**	3.28 .07	0.53 .47
I didn't like hearing my voice	**$\chi^2(1,N=83)$** **Sig**	4.67 .03*	3.95 .05*
My voice sounded strange to me	**$\chi^2(1,N=83)$** **Sig**	3.88 .05*	0.96 .33

There was too much hustle and bustle – I shut down	**χ^2(1,*N*=83)** **Sig**	0.02 .90	0.18 .67
I was bullied	**χ^2(1,*N*=83)** **Sig**	1.76 .19	1.18 .28
I felt I didn't have much in common with others	**χ^2(1,*N*=83)** **Sig**	0.75 .39	0.28 .59
I didn't have anything to say	**χ^2(1,*N*=83)** **Sig**	0.16 .69	1.70 .19
I didn't like the sound of my voice	**χ^2(1,*N*=83)** **Sig**	2.87 .09	0.75 .39
I was afraid of the repercussions if I spoke	**χ^2(1,*N*=83)** **Sig**	0.56 .46	6.81 <.01**
Nobody expected me to speak	**χ^2(1,*N*=83)** **Sig**	0.03 .87	0.01 .91
I was different to other children	**χ^2(1,*N*=83)** **Sig**	1.35 .25	0.19 .66
What I had to say was less important	**χ^2(1,*N*=83)** **Sig**	4.27 .04*	0.42 .52
People made fun of me	**χ^2(1,*N*=83)** **Sig**	0.29 .59	1.70 .19
I was more sensitive than average to my environment	**χ^2(1,*N*=83)** **Sig**	1.06 .30	0.05 .82
I didn't like showing how I was feeling	**χ^2(1,*N*=83)** **Sig**	0.16 .69	0.04 .84
I was sometimes afraid of the people I couldn't speak to	**χ^2(1,*N*=83)** **Sig**	2.03 .15	4.98 .03*
I found other people overwhelming	**χ^2(1,*N*=83)** **Sig**	1.064 .30	1.38 .24
I was quiet	**χ^2(1,*N*=83)** **Sig**	4.51 .03*	0.07 .79
I was afraid of speaking	**χ^2(1,*N*=83)** **Sig**	0.97 .33	0.16 .69
I was worried about what people thought about me	**χ^2(1,*N*=83)** **Sig**	0.58 .45	0.09 .76†
There is no way to explain it – I just couldn't speak	**χ^2(1,*N*=83)** **Sig**	0.60 .44	0.86 .54†

I was shy	**$\chi^2(1,N=83)$** **Sig**	2.04 .15	1.05 .32†

†Cell frequency less than 5, hence Fisher's exact test reported

Table 34 shows that older participants were significantly more likely to say they didn't like hearing their voice / thought their voice sounded strange. They were also significantly more likely to identify with "being quiet" and to believe what they had to say was less important than what others may have to say. Females were significantly more likely to say they were sometimes afraid of the people they couldn't speak to, and significantly more likely to say they didn't like hearing their voice. Males were significantly less likely to say there were afraid of the repercussions if they spoke.

10. Discussion

The main aim of this predominately exploratory study was to explore the prevalence of SM in adults to explore some of the effects this had on their lives, and to convey, in a generalized way, their experiences. In line with the predictions made, therefore, each of the hypotheses are discussed in turn in section 10.1.

In addition to testing hypotheses, as an exploratory study in a new area of research, other interesting results were identified. These are discussed in section 10.2 onwards, with an emphasis on providing easily interpretable information for clinical practice for psychologists and psychotherapists. In particular, SM is evaluated as a safety behaviour and contrasted with other safety behaviours (e.g. SAD and Anorexia Nervosa.)

10.1. Evaluation of the hypotheses

10.1.1. SM is not solely a childhood disorder (H1)

With a response rate of 83 adults, who all reported having SM when turning 18 years old, this study clearly demonstrates that SM is not solely a childhood disorder. The participants of this study were all affected by SM - albeit to different degrees - into adulthood, and most were still affected by SM at the time of taking part. Indeed, some were still struggling with SM in their 50s.

This contradicts research indicating wholesale recovery from SM by young adulthood (i.e. Steinhausen, et al., 2006) and popular opinion that SM is a solely a childhood condition.

On the basis that the participants of this study were limited to those who both knew about the study from the sources it was advertised on, and who volunteered to participate, it may also be assumed that this sample of 83 adults is only the 'tip of the iceberg' regarding the actual number of adults with SM who exist. The introduction suggested that there may be 20,000 adults with SM in the UK - most sub-clinical, perhaps, or who have found coping strategies. This could still be possible.

10.1.2. SM occurs more frequently in adult females than adult males (H2)

Referring to the body of research on children with SM, the DSM V (APA, 2013) indicates that SM is equally prevalent amongst males and females. An aim of this study, therefore, was to evaluate whether a similarly equal prevalence rate for SM in adults exists, the researcher positing that this was not the case in adults.

The ratio of females to males participating in this study was approximately 4:1, which is a higher gender ratio than reported in *any* study on SM in children. Such studies have shown female:male ratios of 2.4:1 (Wright, 1968); 2.1:1 (Ford, Sladeczek, Carlson, & Kratochwill, 1998); 2:1 (Wilkens, 1985; Wergeland, 1979; Hayden, 1980); 1.7:1 (Tancer, 1992); 1.6:1 (Steinhausen & Juzi, 1996); 1.1:1 (Kolvin & Fundudis, 1981); and 1:1 (Elizur & Perednik, 2003; Bergman, Piacentini, & McCracken, 2002; Kopp & Gillberg, 1997).

The results of this current study, therefore, suggest that the prevalence of SM changes with age and that, based on this sample at least, is more prevalent in females in adulthood.

There exists a 2/3:1 female:male ratio of prevalence for most anxiety disorders by adolescence (Rockhill, et al., 2010) and given the high levels of comorbidity of SM with other anxiety disorders (to be discussed later) found in this study, it seems highly plausible that this is also the case for adolescents and adults with SM. For example Lewinshohn et al. (1998) found that females are already twice as likely, at age six, to have experienced an anxiety disorder compared to males. If SM is an anxiety disorder (which, according to the DSM V (APA, 2013) it is) it would seem inconsistent for the gender ratio in SM in children to be so different. The assertion of a 1:1 gender ratio in the DSM V (APA, 2013) suggests a need for further empirical or genetic research.

If, as suggested by the DSM V (APA, 2013), males and females are equally likely to develop SM in childhood, an explanation for this female bias in adulthood should lie in an apparent reduction in males who deem SM to be a major issue by adulthood, rather than an increase in females who deem SM to be a major issue. In light of this, there are a few potential explanations.

First, males are generally less likely to volunteer health-related information and more likely to self-stigmatize (Pederson & Vogel, 2007). Thus, adult males with SM may have been more reluctant to take part in this kind of research. However, anecdotally, the female:male ratio is also very reflective of the number of enquiries made to iSpeak (the researcher's own online support group for adults and adolescents with SM.)

Second, males with SM may have been more likely to have spontaneously recovered by adulthood; or more likely to receive or response to therapeutic intervention in childhood. From the researcher's point of view - as an adult male with SM - this explanation seems unlikely.

Third, due to the high level of comorbidity with other psychopathologies and SM, identified by this study (again, to be discussed later), SM in adult males may not be the overriding need – other mental health needs in males may have taken precedence. For example, of the 83 participants in this study, only 3 (2 females and 1 male) said they had received a diagnosis of Asperger Syndrome (AS). This was lower than expected. While there appear to be no population studies regarding the rate of rate of comorbidity of SM in AS, anecdotally this is believed to be high (for example see Andersson & Thomsen, 1998; Gillberg, 1989; Wolff, 1995). AS is, predominantly, a male issue - with a ratio of 4:1 males:females (Ehlers & Gillberg, 1993). As such it may be that AS takes precedence for males with AS and SM in adulthood, and AS seen by the sufferer himself as the main issue in his life.

Fourth, the gender bias may reflect a gender difference in the social acceptability of SM / taciturnity in adults; particularly, nowadays, contrasted with more emphasis on verbal communication in children in schools. There is evidence of gender differences in adult social and professional communication (e.g. Maccoby, 1990) which makes it less problematic to be a reticent adult male in male-led social and professional circumstances. SM in adult males may less likely be viewed as a disorder per se and, in a sense, fewer males may feel the need to seek this kind of research. Many participants indicated that taking part gave them a level of succour and/or went a little way to fulfil a need to air their stories. This kind of need will have been some of the drive to take part in this research.

10.1.3. The mean age of onset of SM will be before 4 years, based upon research on SM in children (H3)

The average age of onset in this study was 3.78, which supports previous research on SM in children by Steinhausen and Juzi (1996), Cunningham, et al. (2004), Black and Uhde (1995), and Elizur and Perednik (2003) which, together, described a range of mean onset ages from 2.7 to 4.1 years.

No participant had developed SM in adulthood - the latest age of onset was age 16. As such, this suggests that SM is a condition most often, if not always, first diagnosed or experienced in childhood (in agreement with all other studies on SM.)

In fact, the results showed that more than 80% of adults indicated having developed SM prior to age 4 years with many having described having had SM ‘from birth.’ Given the boundary of ordinary childhood amnesia is age 2-4 years (Davis, Gross, & Hayne, 2008), it would have been impossible for most participants to categorically state that they had SM since birth, unless they were told this was the case (e.g. by a parent.)

10.1.4. Most sufferers of SM will not have received a formal diagnosis (H4)

Approximately a quarter (26.3%) of the participants had received a diagnosis of SM in childhood.

Older participants were also much more unlikely to have received a diagnosis of SM: the mean age of those participants who had received a diagnosis of SM in childhood was ≈24 at the point of taking part in this study; and the mean age of those that did not was ≈37. Given the study was conducted in 2013, this may suggest diagnosis rates may have markedly increased between 1994 and 2007. This may be due to publication of DSM-IV (APA, 1994) having caused an increase of awareness of and research in SM post 1994. It may also be due to the advent of the internet, which exponentially grew over that same period, which makes the study of ostensibly rarer psychological / health conditions easier to conduct. It is worth noting that this current research study would have been impossible to conduct prior to the internet - not least because the internet provides the anonymity required for many adults with SM to air their experiences. Additionally this may be due to efforts made by SMG~CAN and SMIRA to raise public awareness of SM in the last 20 years.

Based upon a meta-analysis of research by Kopp and Gillberg (1997), Remschmidt et al. (2001) and Steinhausen and Juzi (1996), the introduction suggested that approximately a quarter of children with a diagnosis of SM in childhood become young adults with SM (see page 35.)

The current research also shows that only around a quarter of adults with SM received a diagnosis in childhood. One can thus suggest that for each of the ≈1 in 555 children diagnosed with SM in middle childhood, there may be a further ≈1 in 185 who never receive a diagnosis. This study suggests an overall prevalence rate of ≈1 in 138 (i.e. 0.7%) between age 7-15. As such, there may be one selectively mute child in approximately 1 in 5 average primary school classes at KS2, which have an average of 27.0 pupils according to the Department of Education (2011); and one selectively mute pupil in approximately 1 in 7 average secondary school classes, which have an average of 20.4 pupils. As such, SM in children is not a *rare* disorder. Many children with SM cannot tolerate the school environment, it has to be said, and need to be home-schooled.

Notably, in the current study, those diagnosed as children still became adults with SM, even if they received treatment as children. This suggests that any treatment attempted may not predict outcome. Anecdotally, from communications received by the researcher from parents with teenagers with SM and with teenagers with SM via the researcher's own UK-based support group (iSpeak), when a child does get a diagnosis, they are, also, often subsequently told, by clinicians, something along the lines of "you have SM, so we cannot help" or, worse still "you cannot be helped" and "there is nothing we can do." This is a worse outcome than no diagnosis, because it fixes in their minds that they are beyond help. Anecdotally therefore, diagnosis is often not backed up with any therapeutic support.

Of course the lack of system-wide support for children and teenagers with SM is not the “fault” of individual practitioners - e.g. educational psychologists. SM in teenagers (adults aren’t considered at all) is seen to be inveterate, difficult, time-consuming and costly to treat. Thus, presumably for workload-related and fiscal reasons, diagnosis usually entails the end of the therapeutic input rather than the beginning of treatment. A number of parents have explicitly written to the researcher “if only my child had Anorexia, they would be able to get help…” demonstrating that parents feel that anorexia is treated preferentially compared to an equally inveterate condition: SM.

10.1.5. There will be high levels of comorbidity in adults, particularly with other anxiety-related psychopathologies and eating disorders (H5)

There was clear evidence that, based upon self-reports, adults with SM were much more likely than the general population to develop other mood-related and anxiety-related conditions. Most notably, this included depression, anxiety, panic disorder, social anxiety, and PTSD. Interestingly however, females with SM were *not* more likely to develop an eating disorder which the researcher predicted due to the functional similarity between SM and Anorexia Nervosa (AN) in particular, which shall be discussed shortly (see page 116); the shared social-cognitive features between AN and ASDs (Oldershaw, Treasure, Hambrook, Tchanturia, & Schmidt, 2011; Odent, 2010); the postulation made by the researcher that SM, like AN, is a safety behaviour; and a hypothesised genetic relationship between SM, ASDs, AN and SAD.

For a sample size of 66 females with adult SM, 7 reported an eating disorder against an expected value of 6 for the general population. Hypothesis 5 is thus mainly but not fully supported by the data - i.e. there is a high level of comorbidity between SM, anxiety-related psychopathologies, and mood disorders. It may be that a more specific question regarding AN specifically rather than eating disorders as a whole should have been asked; or, perhaps, eating disorders are comorbid with *many* other disorders as well, masking the relationship.

Given that, based on these results, SM can continue at a significant level until at least age 50-60, and children with SM are very significantly more likely to develop other mental health conditions in adulthood as well, there appears to be a very strong case for more therapeutic support to be provided for children with SM within schools, and within CAMHS, as opposed to labelling children with SM as untreatable.

Only 1.2% of the participants felt that adult mental health problems could not have been at least partly avoided by support in childhood, 65.1% believing they could have been completely avoided by, for instance, improved understanding of SM in the school system, and access to counselling or CBT in childhood.

10.1.6. The severity of SM will slowly reduce with age (H6)

As an exploratory study investigating the very long-term outcomes of SM for the first time, the research aimed to evaluate whether the severity of SM reduces with age and, if so, whether it does so for everyone.

For the group as a whole, mean peak severity of SM occurred between 12 and 19 years old. Mean self-reported SM severity was still of significantly greater than '50%' between ages 5 and 34, diminishing relatively linearly from the participants' early 20s to a low level by around age 60. This demonstrates that SM can extend well into adulthood and that, for most but not all participants, virtual recovery was *eventually* forthcoming.

Most participants described *partial* recovery from SM (i.e. a turning point) between the ages of 17 and 26, with a mean age of partial recovery being around 22 years. That said, the oldest participant in this study who reported having experienced no remission at all was 46. Partial recovery is consistent with the findings of Remschmidt et al. (2001) who indicated partial but not complete recovery in a proportion of young adults who had had SM in childhood.

The reasons for partial recovery / the turning point included: change of circumstances such as leaving school or education, finding a life partner, starting work, leaving home, becoming pregnant (which one participant described as causing her to be more outspoken spontaneously) and having children. Alternatively, adults with SM made the conscious choice to persistently challenge or force themselves to speak, usually without any form of professional support. Some adults entered therapy (albeit psychodynamic or humanistic forms of therapy, or CBT) and/or took medication (the SSRNI, Venlaxafine, and SSRIs such as Sertraline were mentioned as significantly helping with disinhibiting speech). Detrimentally, some adults relied on alcohol, occasionally causing problems further down the line. Self-harm, as a coping mechanism, was also mentioned.

Few (three only) indicated spontaneous *partial* recovery without one or more of a significant change of circumstance, period of persistent self-challenge, period of therapeutic intervention and / or period of taking medication.

While for most participants there was a remission of symptoms eventually, there were also a subgroup of participants whose SM continued at a significantly higher level after age 34, diverging from the rest of the group. For these participants the severity of SM did not decrease, continuing at a high level into their 50s. This group of eighteen participants (the minority of participants) described having experienced emotional, physical and/or vicarious abuse (e.g. witnessing domestic violence) in their childhood home. There was no data after this age because the oldest participant who described this kind of experience was in their 50s.

There is a substantial body of evidence which indicates that Early Life Stress (ELS) can predict adverse outcomes across a lifetime, particularly in elevating the risk of mood and anxiety disorders (Hicks, DiRago, Iacono, & McGue, 2009; Kendler, Hettema, Butera, Gardner, & Prescott, 2003; Kendler, et al., 1995). Causes of ELS, including maternal depression, divorce, parental loss, and abuse, are said to have exceptionally longstanding neurocognitive, behavioural, and developmental effects.

This research may indicate, therefore, that ELS may be a contributing factor in maintaining the duration and severity of *some cases of* SM, as it is in other anxiety disorders. In this sample, approximately 22% of adult participants with SM indicated they experienced abuse in their childhood home.

10.1.7. SM is not limited to school / educational settings (H7)

The results demonstrated that SM is not just limited to school and educational settings, which is an often-used stereotype - still maintained in DSM V (APA, 2013).

Adults with SM experienced muteness in a wide variety of situations / settings. For sufferers of SM, 'situation' is generally the presence of a given person / variety of people. Adults with SM said often said they experienced muteness in various settings including with first-degree relatives, second-degree relatives, strangers and the opposite sex, with professionals such as doctors, and so on. This is consistent with Mulligan (2012.) In fact mutism in the home environment is not rare according to this research, even though it is very rarely mentioned in prior research (an example is given in Motavelli, 1995).

A binary logistic regression indicated that reasons for mutism for first-degree relatives at age 18 include having experienced emotional, physical or vicarious abuse within the childhood home environment. However, there are other causes for mutism in the home environment including participants suggesting they had ‘autistic traits’. It is important to note that, of the data collected, factors such as abuse and ‘autistic traits’ do not fully predict muteness at home at age 18. The binary logistic regression yielded a pseudo R^2 value of .44.

One should thus not make blanket assumptions regarding being mute in the home environment being entirely predictive of abuse in that environment. SM is a complex disorder; and would need a very much more accurate data-collection instrument to evaluate every possibility. The regression result is an exploratory one only - and is not intended to be used when making clinical decisions. The take home message however is that SM is often not limited to school settings, either in children or adults.

10.1.8. SM is not a form of SAD, but is often comorbid with / develops into SAD (H8)

Comparing self-reported severities of SM and SAD/Social Phobia indicated that virtually every participant experienced a significant level of both SM and SAD/SP *by* around age 12. Prior to age 12 however, there were differences between those participants who said SM is a form of SAD compared to those who did not, as shown in Table 35.

Table 35 — Comparison of findings between those who said SM is a form of social phobia and those who did not

Said SM is a form of social phobia	Did not say SM is a form of social phobia
This larger group (72.3% of the participants) indicated they had statistically significantly higher SP than SM up until age 12.	This smaller group (27.7% of the participants) indicated that they had statistically significantly higher SM than SP up to age 12.
For this group, it may indicate that SM was a result of having precocious social anxiety.	For this group it may indicate that social anxiety was a result of having SM – i.e. they developed social anxiety because they were unable to speak in certain situations, rather than were unable to speak because they were socially anxious per se.
This group represents early onset SP (prior to age 4) coinciding with or leading ordinary onset SM. For this group it would be very difficult to argue that SP and SM are different.	This group represents ordinary onset SM (prior to age 4), and ordinary onset SP, which is generally of teenage onset (Thyer, Parrish, Curtis, Nesse, & Cameron, 1985).
Disagree with the hypothesis: most adults with SM believe SM to be a form of social anxiety.	Agree with the hypothesis: the reported life experience of a minority of participants indicates that SM is differentiable from social anxiety, particularly prior to age 12.

Each participant provided up to 14 measures of SM and SP severity by retrospectively self-reporting the severity of their experience at various ages in the past. There was a high correlation between SM and SP severities for those who indicated their SM was a form of social phobia. However there was a striking *lack* of correlation between SM and SP severities, for those who said their SM was not a form of social phobia. While a lack of correlation is not a ‘statistical result’ per se – at least not one which can be reported with a statistical significance - this does, however, indicate that there is high variation between SM vs. SP severity pattern for a subset of those suffering from SM.

Interestingly, many in both groups indicated that they experienced SP *long before* the ordinary onset of SP - SP generally having a teenage onset (Thyer, Parrish, Curtis, Nesse,

& Cameron, 1985); and many suggesting that they had SP from birth. As such, this research provides evidence that SM may have begun as an early-onset form of SP for many adults with SM. Not all, however – some reporting they always had SM but only developed SAD in their teenage years.

Reading the text received revealed many experiences in SM which are common in SAD and AN also: feelings of undesirability or defectiveness, having unrelenting standards (e.g. there were several instances of body dysmorphia and perfectionism), experiencing embarrassment and shame, having feelings of lack of entitlement (e.g. not feeling that what they thought was as important as others), and so on (e.g. see Pinto-Goueveia, Castilho, Galhardo, & Cunha, 2006).

In summary while there are statistically significant differences between SM and SP severities prior to age 12, most adults with SM experience very similar levels of SP and SM after age 12. However there remains a very specific emphasis on voice and being mute in SM - SM has a distinct behavioural signature (i.e. reliance on mutism / reaction to social stress by instinctively becoming mute) which often does not disappear by adulthood.

10.1.9. SM is the result of a G × E interaction, hence is partly genetic (H9)

The results showed that, for most adults with SM, there was no specific reason for the development of the condition – despite the longstanding nature of the condition, and despite the emotional difficulties and unpleasant repercussions that being situationally mute entails. As such, in the majority of cases SM may be due to an intrinsic, possibly neurocognitive / temperamental difference and/or a result of social learning.

Further genetic research (only a few studies have taken place so far) would be necessary in order to demonstrate that SM has genetic causes. It is important to note however that, while no fathers took part in the study who said they had children with SM, seven mothers took part who had children with SM. This may implicate a genetic cause for some instances of SM and/or it may indicate that social learning is involved in the development and/or maintenance of the condition (or, more likely, a combination of both).

Regarding environmental factors, 41% of participants indicated *bullying* as a contributing factor in their experience of SM. Bullying is said to be predictive of social anxiety in adulthood (e.g. Boulton, 2013); thus it may equally be a compounding factor in the maintenance of SM (Manassis, 2009; Omdal, 2007). Bullying is a strong form of usually emotional abuse and, of course, can have significant long-term behavioural and anxiety ramifications.

Additionally, 22% of the participants related their experience having been caused or compounded by abuse in childhood (emotional, physical and/or vicarious) within the family home. No participant disclosed child sexual abuse (CSA) in the home environment. A couple of participants indicated sexual attacks (e.g. molestation / rape) outside the home environment however, as a contributory factor, because they did not receive help at the time.

This disagrees with much prior research which suggests that abuse is only *rarely* an associated factor in the development of SM (Gordon, 2001; Steinhausen & Juzi, 1996; Kolvin & Fundudis, 1981). And it agrees with other research which suggests that life events, abuse, and unresolved psychodynamic conflicts are a factor (Omdal, 2007; Dow, Sonies, Scheib, Moss, & Leonard, 1995; Krohn, Weckstein, & Wright, 1992). According to the current research, the reality seems to be that of the middle ground: for some (approximately a quarter) abuse is a factor; and for the majority abuse is not a factor. Bullying is a contributory factor for many.

Those who experienced abuse within the childhood home were also more likely to say they developed comorbid social phobia than those who did not, which may further explain why the severity of their SM did not decrease in middle adulthood (i.e. because it is compounded by SAD) and why the severity of the SM of these participants diverged from the others.

According to the NSPCC (NSPCC, 2013) 25.3% of young adults were severely mistreated during childhood. One can suggest, therefore, that the rate of mistreatment of children with SM is unlikely to be significantly different than the population average. As such, while SM *is* a significant factor in some instances of SM, adults with SM are *not* more likely to have experienced abuse. These two statements are not at all contradictory:

simply, one cannot assume that someone with SM is more or less likely to have experienced abuse. This is entirely consistent with, for instance, Black and Udhe (1995) who state “there is no reason to assume that abuse is *any more likely* to be occurring with these children than with the average child.”

There are historical reasons why reporting abuse at all in relation to SM is contentious – i.e. because anecdotally-speaking SM was, in the past, often assumed to be due to abuse (usually sexual abuse) when it was not. This, naturally, caused parents to be reluctant to seek help for children suffering from SM for fear of wrongly being accused of mistreating them. Anecdotally, some parents still have this fear; and an invaluable future area of research would be to evaluate the fears (and other experiences) of parents of children with SM in relation to seeking help for their children. The current research shows that older participants were less likely have had help sought for them by their parents in childhood. However, this may have been the result of a lack of awareness of SM in the past as well.

A number of adult participants who took part in the study expressed the difficulty they felt in expressing the abuse they had been subject to in childhood in relation to the SM they also experienced, in a climate in which most organizations for SM (which are generally run by parents of children with SM) state, for the protection of parents of children with SM, that “there is no evidence that selective mutism is caused by abuse or neglect by parents” - for instance see Jones (2013).

The wording of the NHS Choices page on SM (NHS, 2012) is fairer: “there is no evidence to suggest that children with SM *are more likely* to have suffered abuse, neglect or trauma than any other child”, the researcher having worked with the author (Maggie Johnson) to modify the original wording.

It is important not to *overstate* abuse in relation to SM for the sake of the majority of exemplary parents of children with SM and their children. Yet, it is also important for organizations representing SM not to ostracize (by denying the existence of) those adults who did experience mistreatment as children, for whom mistreatment led to the creation and/or maintenance of their condition (SM is a G × E interaction); and for whom SM, compounded by other anxiety / mood disorders, is an ongoing factor in their lives.

10.1.10. SM in adults is not limited to western cultures (i.e. is worldwide, unlike Anorexia Nervosa) (H10)

By advertising this study online in English and French, the reach of this research was potentially worldwide. Predominately taking part from English-speaking countries (the UK in particular) participants took part from 11 countries. Two of the participants had moved country: one from Poland to the UK; another from Germany to Australia.

If one allies this to the literature review which indicates studies on SM in many countries, it seems there is a case to be made that SM is a worldwide phenomenon, unlike Anorexia Nervosa which is primarily a western phenomenon (Derenne & Beresin, 2006; Habernas, 1996).

10.1.11. Summary of findings

The following table summarises the hypotheses and related findings for easy reference.

Table 36 — Summary of findings

Hypothesis	Met	Summary
H1: SM is not solely a childhood disorder	Yes	The whole dissertation demonstrates that SM is not solely a childhood disorder. SM affects a considerable number of adults – 83 is the "tip of iceberg".
H2: SM occurs more frequently in adult females than adult males	Yes	The research shows that there is, potentially, a ratio of up to 4:1 adult females to males with SM.
H3: The mean age of onset of SM will be before 4 years, based upon research on SM in children	Yes	The age of onset, in agreement with studies on SM in children, was age 3.78 for this sample.
H4: Most sufferers of SM will not have received a formal diagnosis	Yes, older participants in particular	Older participants in particular did not receive a diagnosis. While diagnosis may be increasing, however, there is no evidence that diagnosis predicts long-term outcome, suggesting that the help that follows diagnosis may often be ineffective.
H5: There will be high levels of comorbidity in adults, particularly with other anxiety-related psychopathologies and eating disorders	Higher levels of comorbidity with anxiety and mood disorders, but not eating disorders	Adults with SM experienced significantly higher levels of comorbidity with anxiety and mood disorders than the rest of the population. Women with SM did *not* appear to be significantly more likely to develop an eating disorder, as the researcher hypothesised due to the functional similarities between SM and Anorexia Nervosa.
H6: The severity of SM will slowly reduce with age	This results were more complex than the hypothesis	The results showed that the severity of SM extended well into adulthood, reducing almost linearly from peak severity (teenage and early twenties) to age 60. However, some of those who reported experiencing abuse in the childhood home experienced SM unremittingly into their 50s.
H7: SM is not limited to school / educational settings	Yes	Adults with SM will not, of course, only experience SM in school / educational settings. This research therefore explicitly challenges the stereotype that SM is just an issue "with school".

H8: SM is not a form of SAD, but is often comorbid with / develops into SAD	Yes, but for a minority of the participants only.	Many adults with SM experienced social anxiety at a high level long before the ordinary onset of SAD. For this group it is likely that SM is a form of, or expression of, or means to regulate, social anxiety. There were strong correlations between SM and SP severities for this group. On the other hand, for a smaller group SAD appears to have been preceded by SM. SAD was a factor for the majority of participants post age 12, and is likely to compound the duration of SM. SM has a distinct behavioural signature – i.e. is marked by muteness – which continues long into adulthood.
H9: SM is the result of a G × E interaction, hence is partly genetic	This is likely	Most adults with SM did not experience a significant trigger or environment factors which created / compounded their experience of SM. Additionally, 7 mothers of children with SM took part in this study – indicating a genetic or social-learning aspect to SM. However, many participants indicated that bullying was a factor in their experience. 22% also indicated that abuse in the childhood home (emotional, physical, and/or vicarious) was factor in their experience of SM.
H10: SM in adults is not limited to western cultures (i.e. is worldwide, unlike Anorexia Nervosa)	This is likely	The literature search combined with the number of countries from which participants took part suggests that SM is a worldwide phenomenon.

10.2. Other interesting results and/or aspects of SM to consider

10.2.1. SM as a safety behaviour (clinical implications and suggestions for treatment)

The research showed that mutism is not chosen behaviour. Children and adults do not ‘choose’ to be mute; rather they are trapped *in silence* by their fears.

As such, the researcher postulates that like other disorders in its class (e.g. SAD and potentially AN) one should view SM as a safety behaviour, which has clinical implications and explains why many treatments for SM in children work to some degree - such as sliding in, stimulus fading and shaping (see Johnson & Wintgens, 2001) – each of which enable a child to safely challenge a behaviour that intrinsically maintains safety / avoids fear / avoids the discomfort of social exposure.

There are variety ways the researcher suggests to provide treatments for adolescents and adults with SM: using whispering and low volume to begin with; loosening up through physical activity (perhaps sport) and / or making other noises – preferably loud ones!; using art therapy; *reading* aloud; and acting.

Regarding reading aloud: it is often easier for teenagers and adults to *read* aloud than talk about themselves, because it moves the emphasis away from every aspect of their 'observable selves' besides voice. This is the way that the researcher himself began to speak again in his early 20s, having to invent a 'therapy' for himself because no support existed. In such a way one can work on voice volume and voice confidence only. From the researcher's own experience, being mute for a considerable amount of time often gives rise to voice phobia: i.e. fear of hearing one's own voice. As such, many adults with SM dislike their voices as many adults with AN dislike their bodies. From personal experience, it can feel like an out-of-body-experience to speak again after a long time; one's voice does not feel connected to oneself.

In the opinion of the researcher, an experiencer of SM, people with SM are *not* too afraid to speak; rather they are more afraid to begin speaking in a situation they haven't before, when their instinct (and developed sense of safety) is to *be mute*. This is a subtle difference. They are afraid of the fear they will feel if they attempt speech – i.e. it is an anticipatory fear, once mute, of re-experiencing the same fear that rendered them mute in the first place. Clearly therefore, one could describe SM as a safety behaviour which is both created and maintained by the avoidance of a single fear.

For sufferers of SM it is much easier (as with many safety behaviours) to maintain the behaviour, avoid the discomfort of fear, and to remain mute. This also ties in with conceptualizing SM as a phobia of expressive language (Omdal & Galloway, 2008). In the researcher's opinion, SM is a fear of expressiveness in all forms; and sufferers are afraid to attempt to break such fears because of the anticipatory fear they feel if they were to try.

At this point it is worth indicating that, from a biological perspective, the expectation of being mute, along with the anticipation experienced when contemplating breaking one's silence, may both cause limbic system activation – a facet of anticipatory anxiety (see Yang, et al., 2012).

From a cognitive perspective, in the researcher's opinion, sufferers of SM are afraid of fear through a very circular cognitive process thus - borrowing the use of the word exposure from Exposure Anxiety (EA), a term coined by Donna Williams (Williams, 2008): I fear *exposure*; however if I convey that fear to others I will be further *exposed*. To avoid exposure, I cannot make a sound and I cannot move. If I *ever* subsequently spoke or moved, I would be *exposed*… Particularly for males, this process does not reach conscious thought and the fear is extinguished extremely quickly. This research shows that males do not generally experience the more physiological feelings that females do: a lump in the throat, or a burning sensation in the chest, etc. They are merely mute.

This response is clearly also very close to the freeze-defence of animals. In the researcher's opinion, SM is a 'threat response' to a primal fear of exposure. Rather than a fear of social-evaluation per se this seems more allied to the evaluative threat of a predator – and, thus, in biological terms may be triggered by the dorsal pathway. Neuroimaging techniques may, in time, tell us something about the evaluative threat experienced by sufferers of SM (which may, in fact, be very similar to the evaluative threat experienced by sufferers of SAD) and indicate how this relates to speech. No such studies have been conducted yet, however. An interesting study by Saur et al. (2008) indicates dual ventral and dorsal pathways for language processing; perhaps there are multiple pathways for speech production, one or more of which can be interfered with by anticipatory anxiety.

In summary, the researcher intends to convey that the initial response of muteness is not a conscious process. It is instant because, in a sense, nothing has to happen. Only subsequently to muteness does one's rational mind contemplate being mute, and feels unable to overcome the fear that beginning to speak would bring with it. As such the initial trigger in SM seems to operate by a cognitive shortcut such as an Amygdala Hijack (Goleman, 1996) or, relatedly, a freeze defence reaction. Yet at the same time SM is also similar to SAD, because the scrutinizers / triggers are – after all – always other human beings. Furthermore, once mute one becomes aware that, actually, the response is counterproductive and one's muteness evokes unwelcome scrutiny anyway. Nonetheless it still feels far 'safer' not to *attempt* to speak.

Incidentally, sufferers with SM often have great affinity with their pets, and find great succour in their pets and other animals. For instance see BBC (2012). The author himself owes a great deal to his childhood pet, Blue - a Blue-Merle rough collie.

Regardless of whether one views SM as a form of SAD in the first place, or does not, being mute in the same situation over and over again gives rise to SAD in any case, eventually, because the fear of being different - i.e. the fear of social exclusion (Maner, DeWall, Baumeister, & Schaller, 2007) - and continual "failure" to connect like everyone else is very relevant to someone who cannot speak.

10.2.2. The functional similarity between SM and Anorexia Nervosa

This section contains a more theoretical and 'experimentally' introspective discussion made from the researcher's point of view, as a long-term sufferer of SM (though not AN), regarding the functional similarity between SM and AN. As such, while this section refers to prior research, it is principally based on the introspection of the researcher himself.

Both SM and AN are psychological processes which are difficult to get out of, though *logical* and *instinctual* to get into. As such, SM and AN could be deemed psychological latches - i.e. behaviours which are also, very close, functionally speaking, to addictions which are maintained by safety behaviours and feel insurmountable and inescapable. Children with SM are indeed sometimes likened to Silence Users (e.g. Roe, 2011).

Psychological latches are two-part processes which consist of (a) the **trigger** followed by (b) the **latch**. The trigger is a logical / instinctive reaction to a given fear (e.g. the fear of exposure); and the latch being the maintenance of the behaviour based on fear of re-experiencing the same fear (e.g. hiding and never coming out again, because of the fear of exposure).

As psychological latches, it is possible to describe SM and AN in very similar terms, as given below:

In Anorexia (the more well-known and better understood condition):

> **Trigger:** I am discomfited by negative appraisal of my weight and body-shape therefore [logically + instinctively] I shall not eat, so I can be thinner [hence less negatively appraised].
>
> **Latch:** I am [still, though thinner] discomfited by negative appraisal of my weight and body-shape; and if I ever ate I would be fatter than I am, and my weight and body-shape would *more* negatively be appraised than now, therefore I can never eat again regardless of the repercussions to my health.

In SM (which is, in many sense, an anachronistic extension of the basic fear of exposure which causes young children to hide behind their parent's trouser-legs):

> **Trigger:** I am discomfited and afraid of scrutiny of my inner-self therefore [logically + instinctively] I cannot communicate and expose myself.
>
> **Latch:** I am [still, though mute] discomfited and afraid of scrutiny of my inner-self. If I ever spoke I would be more exposed: my 'self' would more scrutinized than now. Therefore I can never speak again regardless of the repercussions to my mental health.

One could say that anorexia is to food intake as SM is to intake of appraisal of the inner self. Of course psychodynamically-speaking both eating and speaking are oral activities, though that discussion will be left for another time!

Roth and Heimberg (2001) suggested that SAD patients fear appraisal of the observable self rather than the audience per se. The same may be the case for those with SM and AN too. The link should be made (which was suggested in the introduction to this dissertation) between SM and AN; and a link should be made between safety behaviours and SM.

Extrapolating the notion of the observable self to SM and eating disorders, the observable self can be broken into three distinct aspects having denuded oneself of clothes and ancillary abilities such as the ability to write: one's body (one's outer-self), one's voice (which exposes one's inner-self), and one's body language (halfway between both). Thus the 'observable' self includes body shape and weight – i.e. the sensitivities of those with AN plus other eating disorders; and it includes voice and body language – i.e.

the sensitivities of those with SM. Thus AN is to body-concept as SM is to self-concept / concept of one's inner self. Both SM and AN are fears of exposure / scrutiny / evaluation by others but with different emphases.

Not all children / adults with SM have issues with facial communication and body language it should be noted. And many become consummate mimes and use non-vocal communication with no discomfort whatsoever. In such cases, they have a specific fear of using their voice (because it exposes their inner-selves); however, they have no such fear regarding using non-verbal communication (because it does not expose their inner-selves). This explains in a simple way why many with SM do not appear to be at the extreme end of the SAD spectrum (Mulligan & Christner, 2005) – i.e. because they aren't! Their fears are just more specific – i.e. regarding the 'inner' aspects of their observable selves *exposed* through voice.

One could thus say that SM is a disorder of self-awareness (perhaps developing via precocious or intense self-awareness); AN is a disorder of body-awareness (perhaps developing via intense body-awareness); and SAD is an overarching disorder of social-awareness. As such, they are all members of the same logical cluster of conditions regarding relating to and being observed by the outside world, influenced by similar factors including innate perception (NB: perception-distortion and individual differences in functioning of the amygdala may be a factor of all three), emotional makeup, life experience and a lifetime of interpersonal interactions. Yet they are each different and have different emphases. SM and SAD are not *quite* the same thing, though they are indubitably similar.

10.2.3. SM is a misnomer (SM affects all communication not just speech)

Anecdotally speaking, SM is a misnomer, because it can affect communication in all its guises eventually – including speech, body language, and even written forms of communication.

One of the worst aspects of SM, from a sufferer's point of view, is that the condition can prohibit asking others for help via any method (not just speech). For young adults who are selectively mute (particularly those who do not have the support or awareness of their parents), this is a dangerous and exceedingly mentally injurious position to be in.

Anecdotally speaking, there are rare cases, for instance, where rather than ask for help, young people have tried to take their own lives in the knowledge that (a) if they die they do not need the help; (b) if they live they will get the help without asking and speaking. The fear of breaching one's silence can feel so insurmountable that suicide and other desperate measures can seem logical at the time.

In teenagers in particular SM requires parents to be vigilant about this condition and attempt to find support for their children and themselves (peer support from other parents is very valuable). That said, parents are in the unenviable position of encountering a dire lack of availability of knowledgeable clinicians (psychologists among them) when they attempt to seek help.

For instance, in the counselling profession there is no clinical understanding of SM. By way of example, if one searches the Counselling Directory at this juncture one will find one counsellor claiming to have experience of Elective Mutism (a term which has not been used since 1994 – i.e. one which is 20 years out of date). Nothing else!

10.2.4. Therapy and medication

Some participants indicated that partial improvement was due to entering therapy. For adults the kind of therapy does not seem to matter: psychodynamic, CBT, and humanistic therapies were mentioned. Speech-therapy was seldom mentioned, primarily because speech-therapy is exceedingly unlikely to be offered to an adult with SM.

Every participant who mentioned taking SSRIs mentioned their beneficial effects; and of course there is a raft of work citing the beneficial results of SSRIs, generally fluoxetine, on children with SM (e.g. Manassis & Avery, SSRIs in a case of selective mutism, 2013; Motavelli, 1995; Wright, Cucearo, Leonhardt, Kendall, & Anderson, 1995). That said, the risks of taking SSRIs should always be considered – not least regarding SSRI discontinuation syndrome – which occurs in children also (Diler & Avci, 2002).

10.3. Evaluation of the research methodology and data collection instruments

For an exploratory study the questionnaires worked extremely well. The quality of the data received, due to the commitment and dedication of those who took part, was excellent. The large amount of text data received, which shall be analysed more fully in subsequent work, also serves to validate the statistical data, in that it is clear from reading the text that *all* of the participants experienced SM in childhood and continued to do so into adulthood.

The design of the first questionnaire was such that it was unlikely that anyone who did not have first-hand experience of SM would have the experiential knowledge to complete it. For instance, items such as “when you were mute, how did you communicate?” would deter those with social phobia alone rather than SM from completing the survey.

The one aspect of the questionnaire which the researcher would have done differently would be to extend the questionnaire to include an attachment-style measure. It was not possible to discern attachment styles based on speech pattern, which the researcher began to consider while collecting the data (wondering whether those who believed SM was not a form of social anxiety, or who experienced abuse in childhood, might be more likely to express a more avoidant attachment style). It would be an excellent area of future research to evaluate attachment and SM, SM having been likened to an insecure attachment style by earlier researchers.

10.4. Limitations of the study

Because of the nature of the condition itself, the relative rarity of adults with SM, and, hence, the distances involved to carry out face-to-face interviews, make these problematic to conduct in a ‘normal’ face-to-face way. As such this was an online study only. That said, many participants spent a significant length of time, expatiating their life experiences, and providing a wealth of invaluable information.

Many adults with SM find communication per se a problem, and many cannot communicate - even via the anonymity of the internet. Some will have felt too uncomfortable to take part in a research study. As such, a limitation is that the study only drew from that subset of adults with SM who were reachable enough to write about themselves. The researcher was aware of a number of adults with SM who were not able to take part, because of the nature of their condition and / or the circumstances in which they lived.

The researcher did not have the time or available word-count to evaluate every aspect of the qualitative data. The qualitative data, however, shall be the focus of future research, as indicated below.

10.5. Future areas of research

There are many areas for further research (see Table 37), some of which were suggested by participants rather than the researcher. None of the ideas for research seem to have been undertaken to date. The researcher intends to undertake future research in many of these areas in the future.

Table 37 — Future areas of research (provided by the researcher and participants)

Suggested by	Area of research
Researcher	Evaluate the relationship between SM and eating disorders further (specifically anorexia nervosa)
Researcher	Evaluate the prevalence of SM in ASDs such as Asperger Syndrome (AS), contrasting this with the prevalence of eating disorders and SAD in AS. The researcher posits that eating disorders, ASDs, SAD, and SM are common in AS and share a genetic basis.
Researcher	Evaluate the relationship between SM and safety behaviours further. There appears to be no research on SM being a safety behaviour until the current study, which most anxiety disorders are and additionally which some eating disorders are suggested to be.
Researcher	Evaluate attachment behaviour and SM. Prior research suggests that SM is indicative of an insecure attachment style. The researcher posits that there will be some with SM who exhibit an avoidant attachment style.
Researcher	Evaluate the text already received to evaluate further themes and express more thoroughly the individual experiences of those who experienced SM into adulthood. If the word count were unlimited, significantly more of this information would have been incorporated into this dissertation. Such research may will provide further information, also, on how adults with SM tried and partially succeeded to overcome SM.
Researcher	To further evaluate the relationship between shyness and SM (data already collected.)
Researcher	Research the experiences of parents of children with SM.
Participant	Evaluate physiological factors involved in SM
Participant	Evaluate the relationship between SM and OCD.
Participant	Evaluate the social, living situation and financial status of young adults with the condition.
Participant	Evaluate the outcomes of therapy for children and adults with SM.
Participant	Are art therapies like music, drama or art work a way forward to work with sufferers of SM?
Participant	Evaluate the link between selective mutism and aggressive behaviour in childhood.

Participant	Evaluate numbers of participants in different parts of the UK, evaluating where the “good” services are, in order to fight for better services where they are needed.
Participant	Evaluate the hereditary or social-learning aspects of SM further. Seven participants were mothers with SM who had children with SM.
Participant	Evaluate support for and accommodation of SM in the workplace.
Participant	Evaluate how art depicts SM.

11. Conclusions

The current research was an exploratory study into the lived experiences of adults with Selective Mutism (people who have lived with the condition for 30, 40, or 50 years or more). The research suggests that, in the future, adults with SM should be looked towards as an invaluable source of information to psychologists and others conducting research in the field, for the benefit of children, adolescents, and adults with SM alike.

The current research is a collection of firsts including, but not limited to, being (a) the first research to convey experiences of SM directly, not through a third party, such as a parent; (b) the first, truly long-term evaluation of outcomes of SM in adulthood; (c) the first study to evaluate comorbidity with SM in adulthood; and (d) the first study to suggest that SM could be conceptualized as both a safety behaviour and a G × E interaction, synthesizing past conceptualizations of SM together rather than limiting conceptualization of SM to being an anxiety disorder, social anxiety disorder, freeze defence, attachment behaviour, or innate neurophysiological / neurocognitive difference - none of which seem to cover the whole story of SM but each of which covers part of the story.

This research is not the end of the story however. As an exploratory study, the research suggests many areas of research for the future including evaluating the relationships between a constellation of conditions which may have a common genetic basis: Selective Mutism, Social Anxiety Disorder, Anorexia Nervosa, and Asperger Syndrome.

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13. Appendices

This section contains ancillary information which the reader might find useful to refer to when reading the dissertation.

Appendix A. Original research proposal

A.1. Introduction

The proposed research relates to Selective Mutism (SM) in adults. I, the Principal Investigator, am in a relatively unique position to undertake this research as I am, both, an adult with SM and I also run an online support group for adults and teenagers with SM (http://www.ispeak.org.uk/), which was recently linked to by NHS Choices (NHS, 2012).

The research is necessary because there is so little inclusion in academic literature of the experiences of sufferers of SM from a first-hand perspective, and none at all from the first-hand perspectives of adult sufferers of SM who can, perhaps, report the most information about their condition. The only three examples of inclusion seem to be studies by Omdal (2007) and Omdal and Galloway (2007), relating the first-hand experiences of adults who had SM in childhood and have now recovered; and Roe (2011), relating the first-hand experiences of under 18s with SM. Patterson (2011) also used Personal Construct Theory (Kelly, 1955; 1991) to avoid memory distortion and reinterpretation (Hassan, 2006), with six participants between 13 and 19 years to attempt to create a more objective interpretation of SM from a teenage sufferer's point of view. There is also a research study by Ford et al. (1998), which included 18 adults within an overall sample of 153 people with SM, for quantitative analyses. Ordinarily, adults with SM are simply alluded to in other research studies and books (e.g. Cline & Baldwin, 2004).

SM has undergone various name changes over time: Aphasia Voluntaria (Kußmaul, 1877); Elective Mutism (Tramer, 1934); and Selective Mutism (Hesselman, 1973; APA, 1994). Over the last twenty years, and corresponding with the change of name in DSM IV (APA, 1994), SM has been re-conceptualized as anxiety-related (Anstendig, 1999), particularly Social Anxiety Disorder (SAD) related (Black & Uhde, 1995; Dummit et al., 1997), rather than a voluntary or elected choice. In the same period of time, the association between SM and trauma in childhood, stressors in childhood, and life experience, in general, has been pointedly deemphasized in favour of a genetically inherited temperamental basis of SM (Kagan & Snidman, 2009), despite occasional studies to the contrary (e.g. Omdal, 2007; Jacobsen, 1995; Hayden, 1980; Goll, 1979; Adams & Glasner, 1954). The more complete picture seems to be that SM has various causes and predisposing factors (Cline & Baldwin, 2004; Viana et al., 2009; Anstendig, 1999), including no cause at all.

SM is a distinct, stable, psychological, communicative and emotional disorder. Regardless of “cause”, SM is an incredibly homogenous behaviour, once initiated, which may be viewed as a self-regulatory means of reducing anxiety (Moldan, 2005; Mulligan & Christner, 2005; Patterson, 2011; Viana et al., 2009). However, from my own experience: when someone is “trapped in silence” in this way, SM can cause acute existential stress.

Besides being a unique piece of research, this proposed research also has contemporary relevance because in May 2013, the APA is provisionally set to subsume SM into SAD. The DSM IV (APA, 2000) currently classifies SM as an “other condition of childhood”.

In my opinion, neither the DSM IV nor the draft DSM V seems to accurately reflect SM, particularly in my own case as an adult whose SM is not derived from Social Anxiety. An aim of this proposed research, therefore, would be to challenge the APA's decision-making process for SM, which is largely based on the research of Bögels et al. (2010), citing SM as an early-onset developmental variant of Social Anxiety and, explicitly, a childhood disorder.

The assumptions put forward by Bögels et al.'s research may have detrimental implications for the treatment of SM for the next 20 years, in potentially losing sight of other distinctive facets of SM: the anxiety-based or physiological "failure to speak" (APA, 1994); voice-phobia (Hayden, 1980); speech-phobia (Halpern et al., 1971); pragmatics (Hungerford et al., 2003); distinctive pre-disposing factors (Cline & Baldwin, 2004; Viana et al. 2009); phobia of "expressive" language (Omdal & Galloway, 2007); the prevalence of SM in Asperger syndrome (Wolff, 1995); the comorbidity of SM and eating disorders (Steinhausen & Juzi, 1996); the comorbidity of SM, OCD and childhood depression (Wong, 2010); the high rate of psychiatric "disturbance" in the families of children with SM (Kolvin & Fundudis, 1981); along with losing sight of other combinatorial lines of enquiry, such as Tourette's and SM (Rupp, 1999); Fragile X and SM (Hagerman et al., 1999); dissociation and SM (Jacobsen, 1995), specific hearing deficiencies and SM (Bar-Haim et al, 2004); to name but a few.

Problems regarding the proposed re-categorization of SM in the DSM V are already highlighted in the observation that children, hence adults, with SM are not necessarily at the extreme end of the Social Anxiety scale (Mulligan & Christner, 2005). This could be expected given the severity of symptom. In addition, the onset of SM is usually between 2.7 and 4.1 years (Cunningham et al., 2004; Garcia et al., 2004; & Kristensen, 2000), whereas the onset of Social Anxiety is, most often, a teenage or adolescent phenomenon (Thyer et al., 1985).

SM has, more recently, been treated by speech therapists in school settings, using behaviourist / psychosocial approaches, such as stimulus fading, shaping, systematic desensitization and self-modelling (Cohan et al., 2006; Johnson & Wintgens, 2001; Kehle et al., 1998; Blum et al., 1998; Richards & Hansen, 1978; Sluckin & Jehu, 1969). However, viewing SM as a childhood variant of SAD may, eventually, favour Child and Adolescent Mental Health Services' (CAHMS) intervention for children with SM, rather than a speech therapy intervention. Anecdotally, parents have reported on iSpeak that CAMHS are currently ill-equipped to support children with SM, lacking expertise in working with this condition. Moreover, IAPT services have, also, reported being unequipped to work with SM in adults.

A.2. Aims and objectives

Entirely contrary to the only long-term outcome study on SM by Steinhausen et al. (2006), which describes a universal decrease in SM symptoms by young adulthood, parents inform iSpeak that some young adults with: SM continue with SM at a severe level; and/or develop agoraphobia; and/or Major Depressive Disorder; and/or General

Anxiety Disorder; and/or AvPD. Young adults, also, very often become 'NEETs' (i.e., not in education, employment or training).

The overall aim of this research is to provide a first conduit for adults with SM to express their own experiences of SM into and during adulthood in academic literature. Similarly, to highlight the difficulty young adults with SM, in particular, have in making a transition into the adult world - many having been entirely mute for the entirety of their school lives or, in rarer cases, having been entirely mute at home.

A further aim will be to create research evidence to use (myself), in raising awareness and understanding of SM in adults within the NHS, IAPT Services, among psychotherapists, counsellors and other health or mental health practitioners, etc. Similarly, to reduce prejudice against adults with SM amongst educators in adult education who, from my own experience (and from anecdotal experiences written to iSpeak), may view adults with SM as uncooperative and disruptive, rather than selectively mute.

A.3. Methodology and methods

Participants

A minimum of 10 participants, aged minimum 18 years, will be recruited from an opportunity sample of selectively mute or "recovered" adults, who accept invitations to participate posted on: iSpeak (http://www.ispeak.org.uk); SMG~CAN (http://www.selectivemutism.org); SMIRA (http://www.smira.org.uk); the Yahoo

Selective Mutism Support Group; and appropriate Facebook groups, such as http://www.facebook.com/pages/Support-Selective-Mutism/167708556616831. In addition, a YouTube video advertising the study will be created and run for the duration of the study. As such, participants may be obtained worldwide.

As most adults over the age of ~30 who have SM, or had SM into adulthood, will never have been formally diagnosed with SM, having had a formal diagnosis will not be a prerequisite for participation in this study. SM is, also, still often misinterpreted as an aspect of another comorbidity (e.g., Autism Spectrum Disorder (ASD), in younger children by clinicians), which may transfer to adults too.

Design and Analysis

The research shall comprise a mixed method approach, comprising both quantitative (frequencies of response) and qualitative analysis, produced from the responses to open-ended questions. The data will be obtained using a variety of methods (e.g., using online questionnaires) into the conscious experiences of adults who are, either, still selectively mute from childhood, or who consider themselves "recovered", having been selectively mute beyond the age of eighteen only; participants will be given a choice for the method they would prefer to use. Responses to the open ended questions will then be analysed using an Interpretative Phenomenological Analysis approach (Smith, Jarman & Osborne, 1999), or Thematic Analysis (Braun & Clarke, 2006) to explore issues relating to "their" personal experiences of SM. Particular areas of interest will include: participants' perceptions of the “cause”, if any, of their SM; experiences of SM prior to adulthood; the factors, in their lives, which contributed to SM continuing into their adult lives; the difficulty of emerging “successfully” into adult life; and any difficulties encountered as an adult with SM.

Ethical considerations

The study will be carried out in accordance with BPS Guidelines. In particular, participants shall be made aware that they must be volunteers. Also, participants will be told that they can withdraw their data at any stage up until data analysis begins. They will also be made aware of plans for dissemination and offered the opportunity to use a ‘pseudonym’ to maintain some anonymity of their data. These pseudonyms may be used when writing up the study. As participation in this study may cause some adults with SM to recall difficult memories, this will be made clear during the recruitment. For those who do chose to participate, however, help lines will be made available for those affected by the content of the questions. Rights to participation, in line with BPS guidelines, will also be made clear.

Procedure

Participants will be invited to participate in several ways, drawing on personal and professional networks associated with SM. First, e-mail invitations shall be sent to all adult members of my own support group (iSpeak). Second, an advertisement will be put on iSpeak inviting participation. Third, a hard-copy of the survey questionnaire will be posted to parents of adults with SM who have already indicated their willingness to take part in this research. Fourth, an invitation and links will be posted on SelectiveMutism.org, SMIRA, the Yahoo Selective Mutism Support Group, and Facebook. Fifth, a text-based invitation video will also be put onto YouTube. Participants will also be given several alternatives to choose from for their preferred method of data collection.

They will be able to: (1) complete an online survey created with Adobe FormsCentral (https://www.acrobat.com/formscentral/en/home.html); or (2) to print off the survey and complete it. In both of these cases, participants will be given the opportunity to, either, use their own name, a pseudo-name or to respond entirely anonymously and submit their responses, either, electronically or, as appropriate, in paper form. Participants can also / alternatively respond by submitting life stories or other information about their experience of SM to me via e-mail or via the post.

As indicated, data shall be obtained using several methods, although in all cases, participants will be able to contribute information entirely anonymously. Guidance on the key areas of interest will be made available to participants who opt to write their own 'life story', which can be submitted, either, via e-mail or post.

A.4. Limitations

Because of the nature of the condition itself, the relative rarity of adults with SM, and, hence, the distances involved to carry out face-to-face interviews, make these problematic to conduct in a 'normal' face-to-face way. Moreover, many adults with SM find communication per se a problem, and many cannot communicate via the internet. As such, a limitation is that I will only be drawing from that subset of adults with SM who are reachable enough to write about themselves. Because of the relatively small sample size and the ostensibly low incidence of SM in adulthood, this is more of an exploratory study than an attempt to quantitatively analyse the occurrences of one pattern of experience of SM over another. The number of adults with SM in existence is, at this stage, an entirely unknown number.

A.5. Timetable

Data collection will start as soon as ethical approval has been obtained. I am already in contact with a number of potential volunteers who very much wish to take part in this research. More volunteers may also sign up as the period of research progresses (i.e., the project will advertise for participants until towards the end of April 2013.)

Appendix B. Participant information sheet

Invitation to take part in Selective Mutism research

Dr C. Sutton (carl@s-m.org.uk) (Researcher)

Dr M. Tytherleigh, C.Psychol., PG Cert (HE)., FHEA., AFBPsS (Research supervisor)

Background

There is currently no inclusion in academic literature of Selective Mutism (SM) in adulthood, SM often (incorrectly) being perceived to be an issue which always automatically resolves itself in childhood.

Adults with SM are generally perceived not to exist and, hence, no specific service or professional support for adults with SM exists, apparently anywhere in the world.

I am looking for adults with SM, or adults who continued to have SM beyond 18 from childhood (or who developed SM in adulthood) who now consider themselves to be recovered, to take part in a research project about SM in adulthood.

I have a personal interest in SM because I am an adult with SM myself. It's something that I've had all of my life, and it’s something that I shall probably have for the remainder of my life. I already have a PhD in Computer Science, but I am undertaking an MSc in Psychology at the University of Chester, with a view, perhaps, to becoming a Clinical

Psychologist in the future. The anonymised responses to the survey will be used to form the basis of my MSc dissertation due in October 2013.

The intended outcomes of the research are:

- To assert the existence of SM in adulthood, in order to challenge the perception that SM is solely a childhood "disorder".
- To investigate the varied ways that SM affects adults with SM, from the individual perspective of the sufferer themself.
- To investigate the varied "reasons" that SM occurs.
- To investigate how adult sufferers of SM conceptualize SM.
- To investigate why SM did not dissipate for adults with SM who still have it.

How to take part

To take part, you can do one (or more) of the following:

- Complete an online survey online before 3rd May 2013
- Download the online survey to complete this by hand and post it to me.
- In addition, or instead, send me your SM 'life story', or other information about your experience of SM. In this instance, you can simply refer to the questions in the survey, but choose to tell me 'your' story in a way that suits you.

If you complete the survey (either online, or by hand) you do NOT have to answer any questions which make you feel uncomfortable. All responses can also be anonymised using a pseudonym, of your choice. Also, if you do take part and return your responses, you can choose to remove your data from the study up until the 3rd May 2013, without needing to provide any explanation for doing so.

If you choose to participate, I hope you will see this as your opportunity to extend the current academic and professional understanding of SM. Very little has been written from the perspective of people with SM, and it's my wish to change that. While the research is for my dissertation, I feel it is more important than just that. It is my long-term intention to create research evidence to effect change in education, in the health system, amongst counsellors, therapists, and psychologists. I sincerely believe that the time you spend taking part in the research will be time well spent.

Important Information

NB: Please note that any information you provide will be disseminated as research, which could include being made available in the public domain (e.g., as a research article, or public information sheet). As such, although your identity will be hidden (e.g., using a pseudonym), you should only include information which you feel comfortable revealing in this way. In addition, as participation in this study may cause some adults with SM to recall difficult memories, you should NOT take part if you feel that participation will be detrimental to your personal and/or emotional well-being.

Thank you for your time in reading this and I hope you do decide to take part. If you have any questions about participation in this study, don’t hesitate to e-mail me.

To participate, please click onto the link that is most appropriate for you:

- To complete the online survey online, please click on: http://www.s-m.org.uk.
- To download the online survey, please click on: http://www.ispeak.org.uk/Research.aspx, and complete this by hand and post it to me via:

C. Sutton (Selective Mutism Survey)
Department of Psychology
University of Chester
Parkgate Road
Chester
CH1 4BJ

Send me your life story or other information about your experience of SM, either by e-mail to carl@s-m.org.uk, or by post (to the address given above)

Carl

Appendix C. Main questionnaire (English)

Appendix D. Follow-up questionnaire (English)

Appendix E. Cross reference between SPSS variables and questionnaire items, including computed variables and data preparation

The following table lists every SPSS variable, cross-referenced with items in the two questionnaires (see Appendix C and Appendix D). Where variables are computed, the SPSS script used for computation is shown.

Table 38 — Cross reference between SPSS variables and questionnaire items

Variable name	**Description**	**Values**	**Source / computation / analysis**
Name	Pseudonym of the participant		Q1. 1.1
Gender	Gender	0=Female, 1=Male	Q1. 2.1
AspergerSyndrome	Has a diagnosis of Asperger Syndrome	0=No, 1=Yes	(Thematic analysis)
Country	Country	0=UK, 1=USA, 2=Australia, 3=Canada, 4=France, 5=Israel, 6=Lebanon, 7=Middle east, 8=Singapore, 9=Spain, 10=US Virgin Islands	Q1 1.4
Age	Age on 3rd May 2013	18..	Q1 2.2
YoungerThanAverage	Whether were younger than average	0=No, 1=Yes	COMPUTE YoungerThanAverage= (Age<33.4).
AgeGroup	Age group	0=18-20, 1=20s, 2=30s, 3=40s, 4=50s, 5=60s	COMPUTE AgeGroup= (Age>=20)+(Age>=30)+(Age>=40)+(Age>=50)+ (Age>=60).
AgeOfOnset	Age of onset		Q1 2.3
AgeOfOnsetRange	Age of onset (by range)	1=0-4, 2=5-8, 3=9-12, 4=13-16	COMPUTE AgeOfOnsetRange= 1+(AgeOfOnset>=5)+(AgeOfOnset>=9)+(AgeOfOnset>=13).
AgeOfOnsetGroup	Age of onset group	1=From birth, 2=Before memory, 3=Within memory	COMPUTE AgeOfOnsetGroup= (FromBirth*1)+(BeforeMemory*2)+(WithinMemory*3).
FromBirth	Whether SM was from birth	0=No, 1=Yes	COMPUTE FromBirth= (AgeOfOnset=0).
BeforeMemory	Onset pre-memory	0=No, 1=Yes	COMPUTE BeforeMemory= (AgeOfOnset<=4).

WithinMemory	SM developed within memory	0=No, 1=Yes	COMPUTE WithinMemory= (AgeOfOnset>4).
AgeOfRealization	Age of realization of difference	0..	Q1 2.4
AgeOfRealizationRange	Age of realization (by range)	1=0-4, 2=5-8, 3=9-12, 4=13-16, 5=17-20, 6=21+	COMPUTE AgeOfRealizationRange = 1+(AgeOfRealization>=5)+(AgeOfRealization>=9)+(AgeOfRealization>=13)+(AgeOfRealization>=17)+(AgeOfRealization>=21).
AgeOfRealizationGroup	Age of realization group	1=From birth, 2=Early (<8), 3=Middle (8-16), 4=Late (>16)	COMPUTE AgeOfRealizationGroup = 1+(AgeOfRealization>0)+(AgeOfRealization>=8)+(AgeOfRealization>=16).
RealizationType	Realization of difference type	0=Couldn't speak, 1=Didn't speak, 2=Others said didn't speak, 3=Fear of speaking, 4=Other	(Thematic analysis)
AgeKnownCond	Age knew had SM	0..	Q1 2.6
Discovery	How discovered SM was a named condition	0=Diagnosed with SM, 1=Child diagnosed with SM, 2=Internet, 3=TV, 4=Books/mags, 5=Other	Q1 2.8 (Thematic analysis)
Diagnosed	Whether have diagnosis	0=No, 1=Yes	(Thematic analysis)
HasChildWithSM	Has a child with SM	0=No, 1=Yes	(Thematic analysis)
AgeSharedCond	Age knew others had SM	0..	Q1 2.7
ImprovementAge	Age of improvement	0..	Q1 4.3
Recovered	Recovered from SM?	0=Recovered, 1=Partly recovered, 2=Not recovered	Q1 4.1
InabilityToSpeak	Whether SM is a situational inability	0=No, 1=Yes	(Thematic analysis)
DueToAnxiety	Due to anxiety / as a means to regulate anxiety	0=No, 1=Yes	(Thematic analysis)
DueToFNE	Due to FNE / social anxiety	0=No, 1=Yes	(Thematic analysis)
WindowToTheSoul	Speech as a window to the soul / conditions of worth	0=No, 1=Yes	(Thematic analysis)
FearOfSpeech	Fear of speech	0=No, 1=Yes	(Thematic analysis)
SubconsciousResponse	Subconscious response / unknown reason	0=No, 1=Yes	(Thematic analysis)
FreezeResponse	Freeze response	0=No, 1=Yes	(Thematic analysis)
Disconnect	Neurological disconnection between thoughts and speech	0=No, 1=Yes	(Thematic analysis)

SlowedThoughts	Slowed thoughts / mind-blankness	0=No, 1=Yes	(Thematic analysis)
FeelingTrapped	Feeling trapped / behind a glass wall	0=No, 1=Yes	(Thematic analysis)
ThroatMouthLocked	Throat blockage / mouth locked	0=No, 1=Yes	(Thematic analysis)
LackOfSocialSkills	Lack of development of social skills	0=No, 1=Yes	(Thematic analysis)
SelfProtection	Self-protection	0=No, 1=Yes	(Thematic analysis)
FeelingIncongruous	Feeling incongruous	0=No, 1=Yes	(Thematic analysis)
PrimaryDefinitionOfSM	Primary definition of SM	2=Due to anxiety/as a means to regulate anxiety 3=Due to FNE/social anxiety 4=Window to the soul/conditions of worth 5=Fear of speech 6=Subconscious response/unknown reason 7=Freeze/stranger response 8=Disconnection between thoughts and speech 9=Slow thoughts/mind-blankness 10=Feeling trapped/behind a glass wall 11=Throat/mouth locked/verbal paralysis 12=Lack of social skills 13=Self-protection 14=Feeling incongruous	(Thematic analysis)
SecondaryDefinitionOfSM	Secondary definition of SM	2=Due to anxiety/as a means to regulate anxiety 3=Due to FNE/social anxiety 4=Window to the soul/conditions of worth 5=Fear of speech 6=Subconscious response/unknown reason 7=Freeze/stranger response 8=Disconnection between thoughts and speech	(Thematic analysis)

		9=Slow thoughts/mind-blankness 10=Feeling trapped/behind a glass wall 11=Throat/mouth locked/verbal paralysis 12=Lack of social skills 13=Self-protection 14=Feeling incongruous	
RecoveryAge	Age of recovery	0…	Q1 4.2
HasRecovered	If recovered	0=No, 1=Yes	Q1 4.1
PartlyRecovered	If partly recovered	0=No, 1=Yes	Q1 4.1
NotRecovered	If not recovered at all	0=No, 1=Yes	Q1 4.1
Describes13	SM is an illness	0=No, 1=Yes	Q1 2.11
Describes9	SM is an "autistic trait"	0=No, 1=Yes	Q1 2.11
Describes7	SM is due to a sensory integration difficulty	0=No, 1=Yes	Q1 2.11
Describes2	SM is a learned behaviour	0=No, 1=Yes	Q1 2.11
Describes1	SM is a genetic difference	0=No, 1=Yes	Q1 2.11
Describes8	SM is an individual difference	0=No, 1=Yes	Q1 2.11
Describes11	SM is a specific phobia	0=No, 1=Yes	Q1 2.11
Describes14	SM is a disability	0=No, 1=Yes	Q1 2.11
Describes17	SM is an emotional problem	0=No, 1=Yes	Q1 2.11
Describes4	SM is a response to life experience	0=No, 1=Yes	Q1 2.11
Describes12	SM is a mental health problem	0=No, 1=Yes	Q1 2.11
Describes15	SM is an avoidant behaviour	0=No, 1=Yes	Q1 2.11
Describes16	SM is a response to my childhood family environment	0=No, 1=Yes	Q1 2.11
Describes10	SM is the outcome of being a highly sensitive person	0=No, 1=Yes	Q1 2.11
Describes3	SM is a way of dealing with anxiety	0=No, 1=Yes	Q1 2.11
Describes5	SM is an anxiety disorder	0=No, 1=Yes	Q1 2.11
Describes18	SM is (Other)	0=No, 1=Yes	Q1 2.11

DescribesNum	Number of describes ticked	0..	COMPUTE DescribesNum= Describes1+Describes2+Describes3+Describes3+Descibes4+Describes5+SMIsSA+Describes7+Describes8+Describes9+Describes10+Describes11+Describes12+Describes13+Describes14+Describes15+Describes16+Describes17+Describes17+Describes18
Because1	Mute because: There is no way to explain it - I just couldn't speak	0=No, 1=Yes	Q1 2.10
Because2	Mute because: I was worried about what people thought about me	0=No, 1=Yes	Q1 2.10
Because3	Mute because: I was sometimes afraid of the people I couldn't speak to	0=No, 1=Yes	Q1 2.10
Because4	Mute because: I was quiet	0=No, 1=Yes	Q1 2.10
Because5	Mute because: There were things I didn't want people to know about me	0=No, 1=Yes	Q1 2.10
Because6	Mute because: I didn't like showing how I was feeling	0=No, 1=Yes	Q1 2.10
Because7	Mute because: My voice sounded strange to me	0=No, 1=Yes	Q1 2.10
Because8	Mute because: People made fun of me	0=No, 1=Yes	Q1 2.10
Because9	Mute because: I found other people overwhelming	0=No, 1=Yes	Q1 2.10
Because10	Mute because: Nobody expected me to speak	0=No, 1=Yes	Q1 2.10
Because11	Mute because: I felt I didn't have much in common with other people	0=No, 1=Yes	Q1 2.10
Because12	Mute because: There was too much hustle and bustle - I shut down	0=No, 1=Yes	Q1 2.10
Because13	Mute because: I was experiencing loss	0=No, 1=Yes	Q1 2.10
Because14	Mute because: People could sense how I felt and I didn't like it	0=No, 1=Yes	Q1 2.10
Because15	Mute because: I was different to other children	0=No, 1=Yes	Q1 2.10
Because16	Mute because: I was afraid of the repercussions if I spoke	0=No, 1=Yes	Q1 2.10

Because17	Mute because: What I had to say was less important or worthwhile than what others had to say	0=No, 1=Yes	Q1 2.10
Because18	Mute because: I was more sensitive than average to my environment	0=No, 1=Yes	Q1 2.10
Because19	Mute because: I was afraid of speaking	0=No, 1=Yes	Q1 2.10
Because20	Mute because: I didn't like the sound of my voice	0=No, 1=Yes	Q1 2.10
Because21	Mute because: I was bullied	0=No, 1=Yes	Q1 2.10
Because22	Mute because: People made fun of my voice	0=No, 1=Yes	Q1 2.10
Because23	Mute because: It was something to do with my mouth or my teeth	0=No, 1=Yes	Q1 2.10
Because24	Mute because: I was shy	0=No, 1=Yes	Q1 2.10
Because25	Mute because: I didn't need to speak - someone else often spoke for me	0=No, 1=Yes	Q1 2.10
Because26	Mute because: I didn't have anything to say	0=No, 1=Yes	Q1 2.10
Because27	Mute because: Other people's anxiety rubbed off on me	0=No, 1=Yes	Q1 2.10
Because28	Mute because: I wasn't allowed to speak sometimes - someone else always took over	0=No, 1=Yes	Q1 2.10
Because29	Mute because: I couldn't speak because I had never spoken to ...	0=No, 1=Yes	Q1 2.10
Because30	Mute because: I didn't like hearing my voice	0=No, 1=Yes	Q1 2.10
Because31	Mute because: I was punished for not speaking	0=No, 1=Yes	Q1 2.10
Because32	Mute because: Other people's emotions were more important than mine	0=No, 1=Yes	Q1 2.10
Because33	Mute because: I felt responsible for another person's emotional welfare	0=No, 1=Yes	Q1 2.10
Because34	Mute because: (Other)	0=No, 1=Yes	Q1 2.10

BecauseNum	Number of because items ticked	0..	COMPUTE BecauseNum= Because1+Because2+Because3+Because4+Because5+Because6+Because7+Because8+Because9+Because10+Because11+Because12+Because13+Because14+Because15+Because16+Because17+Because18+Because19+Because20+Because21+Because22+Because23+Because24+Because25+Because26+Because27+Because28+Because29+Because30+Because31+Because32+Because33+Because34
HowC1	When I couldn't speak ... I didn't communicate	0=No, 1=Yes	Q1 3.7
HowC2	When I couldn't speak ... I wrote things down	0=No, 1=Yes	Q1 3.7
HowC3	When I couldn't speak ... I used rudimentary signing (hand gestures etc.)	0=No, 1=Yes	Q1 3.7
HowC4	When I couldn't speak ... I used an electronic speech aid	0=No, 1=Yes	Q1 3.7
HowC5	When I couldn't speak ... I smiled	0=No, 1=Yes	Q1 3.7
HowC6	When I couldn't speak ... I nodded and shook my head	0=No, 1=Yes	Q1 3.7
HowC7	When I couldn't speak ... I got other people to communicate for me	0=No, 1=Yes	Q1 3.7
HowC8	When I couldn't speak ... I used a toy/puppet to speak for me	0=No, 1=Yes	Q1 3.7
HowC9	When I couldn't speak ... (Other)	0=No, 1=Yes	Q1 3.7
Rating1	SM has affected my life opportunities	-1..1	Q1 2.13
Rating2	I succeeded in life, despite having SM	-1..1	Q1 2.13
Rating3	Without SM, I would have been very different	-1..1	Q1 2.13
Rating4	SM has caused me a lot of emotional distress	-1..1	Q1 2.13
Rating5	I have been ashamed of having SM, which made it even worse	-1..1	Q1 2.13
Rating6	Having SM gets easier as you get older	-1..1	Q1 2.13
Rating7	It is easier to have SM now as a child compared to when I was a child	-1..1	Q1 2.13

Rating8	I blame other people for my SM	-1..1	Q1 2.13
Rating9	SM is something I was born with	-1..1	Q1 2.13
Rating10	SM is something I value	-1..1	Q1 2.13
Rating11	I enjoy silence	-1..1	Q1 2.13
Rating12	I am afraid of silence	-1..1	Q1 2.13
Rating13	I wish I did not have / had not had SM	-1..1	Q1 2.13
Rating14	People with SM are my kind of people	-1..1	Q1 2.13
Trigger	Was there a trigger / environmental circumstances involved	0=Yes, 1=No, 2=Unsure	Q1 3.1
DefiniteTrigger	Definite trigger for muteness	0=No, 1=Yes	COMPUTE DefiniteTrigger= (Trigger=0).
Age10SP4	Couldn't speak to (Age 10): Father	0=No, 1=Yes	Q1 3.3
Age10SP5	Couldn't speak to (Age 10): Mother	0=No, 1=Yes	Q1 3.3
Age10SP6	Couldn't speak to (Age 10): Sibling(s)	0=No, 1=Yes	Q1 3.3
Age10SP7	Couldn't speak to (Age 10): Step-father	0=No, 1=Yes	Q1 3.3
Age10SP8	Couldn't speak to (Age 10): Step-mother	0=No, 1=Yes	Q1 3.3
Age10SP9	Couldn't speak to (Age 10): Step-brother(s) / sister(s)	0=No, 1=Yes	Q1 3.3
Age10SP12	Couldn't speak to (Age 10): Aunties	0=No, 1=Yes	Q1 3.3
Age10SP13	Couldn't speak to (Age 10): Uncles	0=No, 1=Yes	Q1 3.3
Age10SP14	Couldn't speak to (Age 10): Cousins	0=No, 1=Yes	Q1 3.3
Age10SP11	Couldn't speak to (Age 10): Grandfather	0=No, 1=Yes	Q1 3.3
Age10SP10	Couldn't speak to (Age 10): Grandmother	0=No, 1=Yes	Q1 3.3
Age10SP15	Couldn't speak to (Age 10): Other relatives	0=No, 1=Yes	Q1 3.3
Age10SP1	Couldn't speak to (Age 10): Other children at school	0=No, 1=Yes	Q1 3.3

Age10SP20	Couldn't speak to (Age 10): Other children outside school	0=No, 1=Yes	Q1 3.3
Age10SP19	Couldn't speak to (Age 10): The opposite sex	0=No, 1=Yes	Q1 3.3
Age10SP3	Couldn't speak to (Age 10): Teachers	0=No, 1=Yes	Q1 3.3
Age10SP16	Couldn't speak to (Age 10): Strangers	0=No, 1=Yes	Q1 3.3
Age10SP17	Couldn't speak to (Age 10): Doctors	0=No, 1=Yes	Q1 3.3
Age10SP18	Couldn't speak to (Age 10): Other professionals	0=No, 1=Yes	Q1 3.3
Age10SP2	Couldn't speak to (Age 10): In social settings	0=No, 1=Yes	Q1 3.3
Age10SP21	Couldn't speak to (Age 10): (Other)	0=No, 1=Yes	Q1 3.3
Age18SP4	Couldn't speak to (Age 18): Father	0=No, 1=Yes	Q1 4.5
Age18SP5	Couldn't speak to (Age 18): Mother	0=No, 1=Yes	Q1 4.5
Age18SP6	Couldn't speak to (Age 18): Siblings(s)	0=No, 1=Yes	Q1 4.5
Age18SP7	Couldn't speak to (Age 18): Step-father	0=No, 1=Yes	Q1 4.5
Age18SP8	Couldn't speak to (Age 18): Step-mother	0=No, 1=Yes	Q1 4.5
Age18SP9	Couldn't speak to (Age 18): Step-brother(s) / sister(s)	0=No, 1=Yes	Q1 4.5
Age18SP12	Couldn't speak to (Age 18): Aunties	0=No, 1=Yes	Q1 4.5
Age18SP13	Couldn't speak to (Age 18): Uncles	0=No, 1=Yes	Q1 4.5
Age18SP14	Couldn't speak to (Age 18): Cousins	0=No, 1=Yes	Q1 4.5
Age18SP11	Couldn't speak to (Age 18): Grandfather	0=No, 1=Yes	Q1 4.5
Age18SP10	Couldn't speak to (Age 18): Grandmother	0=No, 1=Yes	Q1 4.5
Age18SP15	Couldn't speak to (Age 18): Other relatives	0=No, 1=Yes	Q1 4.5
Age18SP1	Couldn't speak to (Age 18): Other students / colleagues	0=No, 1=Yes	Q1 4.5

Age18SP20	Couldn't speak to (Age 18): Other students / colleagues (outside work)	0=No, 1=Yes	Q1 4.5
Age18SP19	Couldn't speak to (Age 18): The opposite sex	0=No, 1=Yes	Q1 4.5
Age18SP3	Couldn't speak to (Age 18): Teachers / lecturers / bosses	0=No, 1=Yes	Q1 4.5
Age18SP16	Couldn't speak to (Age 18): Strangers	0=No, 1=Yes	Q1 4.5
Age18SP17	Couldn't speak to (Age 18): Doctors	0=No, 1=Yes	Q1 4.5
Age18SP18	Couldn't speak to (Age 18): Other professionals	0=No, 1=Yes	Q1 4.5
Age18SP2	Couldn't speak to (Age 18): In social settings	0=No, 1=Yes	Q1 4.5
Age18SP21	Couldn't speak to (Age 18): (Other)	0=No, 1=Yes	Q1 4.5
NowSP4	Can't speak to (Now): Father	0=No, 1=Yes	Q1 4.8
NowSP5	Can't speak to (Now): Mother	0=No, 1=Yes	Q1 4.8
NowSP6	Can't speak to (Now): Sibling(s)	0=No, 1=Yes	Q1 4.8
NowSP7	Can't speak to (Now): Step-father	0=No, 1=Yes	Q1 4.8
NowSP8	Can't speak to (Now): Step-mother	0=No, 1=Yes	Q1 4.8
NowSP9	Can't speak to (Now): Step-brother(s) / sister(s)	0=No, 1=Yes	Q1 4.8
NowSP12	Can't speak to (Now): Aunties	0=No, 1=Yes	Q1 4.8
NowSP13	Can't speak to (Now): Uncles	0=No, 1=Yes	Q1 4.8
NowSP14	Can't speak to (Now): Cousins	0=No, 1=Yes	Q1 4.8
NowSP11	Can't speak to (Now): Grandfather	0=No, 1=Yes	Q1 4.8
NowSP10	Can't speak to (Now): Grandmother	0=No, 1=Yes	Q1 4.8
NowSP15	Can't speak to (Now): Other relatives	0=No, 1=Yes	Q1 4.8
NowSP1	Can't speak to (Now): Colleagues etc.	0=No, 1=Yes	Q1 4.8

NowSP19	Can't speak to (Now): The opposite sex	0=No, 1=Yes	Q1 4.8
NowSP3	Can't speak to (Now): Bosses etc.	0=No, 1=Yes	Q1 4.8
NowSP16	Can't speak to (Now): Strangers	0=No, 1=Yes	Q1 4.8
NowSP17	Can't speak to (Now): Doctors	0=No, 1=Yes	Q1 4.8
NowSP18	Can't speak to (Now): Other professionals	0=No, 1=Yes	Q1 4.8
NowSP2	Can't speak to (Now): Anyone in a social setting	0=No, 1=Yes	Q1 4.8
NowSP20	Can't speak to (Now): (Other)	0=No, 1=Yes	Q1 4.8
SP15Changed	From age 10, by the time you were about 15 years old, had this pattern changed?	0=No, 1=Yes	Q1 3.4
ChildIssues	In childhood did you have other issues that you were aware of, such as anxiety or depression?	0=No, 1=Yes	Q1 3.8
ChildIssue1	As a child I had ... Depression	0=No, 1=Yes	Q1 3.9
ChildIssue2	As a child I had ... Anxiety	0=No, 1=Yes	Q1 3.9
ChildIssue3	As a child I had ... An eating disorder	0=No, 1=Yes	Q1 3.9
ChildIssue4	As a child I had ... Panic disorder	0=No, 1=Yes	Q1 3.9
ChildIssue5	As a child I had ... Social phobia / social anxiety	0=No, 1=Yes	Q1 3.9
ChildIssue6	As a child I had ... Agoraphobia	0=No, 1=Yes	Q1 3.9
ChildIssue7	As a child I had ... Separation anxiety	0=No, 1=Yes	Q1 3.9
ChildIssue8	As a child I had ... OCD	0=No, 1=Yes	Q1 3.9
ChildIssue9	As a child I had ... Post-traumatic stress disorder	0=No, 1=Yes	Q1 3.9
ChildIssue10	As a child I had ... (Other)	0=No, 1=Yes	Q1 3.9
AdultIssue1	As an adult I have ... Depression	0=No, 1=Yes	COMPUTE AdultIssue1= AdultIssueRel1 | AdultIssueNotRel1
AdultIssue2	As an adult I have ... Anxiety	0=No, 1=Yes	COMPUTE AdultIssue2= AdultIssueRel2 | AdultIssueNotRel2

AdultIssue3	As an adult I have ... An eating disorder	0=No, 1=Yes	COMPUTE AdultIssue3= AdultIssueRel3 | AdultIssueNotRel3
AdultIssue4	As an adult I have ... Panic disorder	0=No, 1=Yes	COMPUTE AdultIssue4= AdultIssueRel4 | AdultIssueNotRel4
AdultIssue5	As an adult I have ... Social phobia / social anxiety	0=No, 1=Yes	COMPUTE AdultIssue5= AdultIssueRel5 | AdultIssueNotRel5
AdultIssue6	As an adult I have ... Agoraphobia	0=No, 1=Yes	COMPUTE AdultIssue6= AdultIssueRel6 | AdultIssueNotRel6
AdultIssue7	As an adult I have ... Separation anxiety	0=No, 1=Yes	COMPUTE AdultIssue7= AdultIssueRel7 | AdultIssueNotRel7
AdultIssue8	As an adult I have ... OCD	0=No, 1=Yes	COMPUTE AdultIssue8= AdultIssueRel8 | AdultIssueNotRel8
AdultIssue9	As an adult I have ... Post-traumatic stress disorder	0=No, 1=Yes	COMPUTE AdultIssue9= AdultIssueRel9 | AdultIssueNotRel9
AdultIssue10	As an adult I have ... (Other)	0=No, 1=Yes	COMPUTE AdultIssue10= AdultIssueRel10 | AdultIssueNotRel10
AdultIssuesRel	I now have other psychological or emotional issues, which directly stemmed from my SM	0=No, 1=Yes	Q1 4.10
AdultIssuesNotRel	I now have other psychological or emotional issues, which did not directly stem from my SM	0=No, 1=Yes	Q1 4.10
AdultIssuesNoOther	I have no other issues	0=No, 1=Yes	Q1 4.10
AdultIssueRel1	Related to SM I have ... Depression	0=No, 1=Yes	Q1 4.11
AdultIssueRel2	Related to SM I have ... Anxiety	0=No, 1=Yes	Q1 4.11
AdultIssueRel3	Related to SM I have ... An eating disorder	0=No, 1=Yes	Q1 4.11
AdultIssueRel4	Related to SM I have ... Panic disorder	0=No, 1=Yes	Q1 4.11
AdultIssueRel5	Related to SM I have ... Social phobia / social anxiety	0=No, 1=Yes	Q1 4.11
AdultIssueRel6	Related to SM I have ... Agoraphobia	0=No, 1=Yes	Q1 4.11
AdultIssueRel7	Related to SM I have ... Separation anxiety	0=No, 1=Yes	Q1 4.11
AdultIssueRel8	Related to SM I have ... OCD	0=No, 1=Yes	Q1 4.11
AdultIssueRel9	Related to SM I have ... Post-traumatic stress disorder	0=No, 1=Yes	Q1 4.11

AdultIssueRel10	Related to SM I have ... (Other)	0=No, 1=Yes	Q1 4.11
CouldHaveAvoided	Do you feel you could have avoided these issues with professional support?	0=Yes, 1=No, 2=Partly, 3=Other	Q1 4.12
AdultIssueNotRel1	Not related to SM I have ... Depression	0=No, 1=Yes	Q1 4.13
AdultIssueNotRel2	Not related to SM I have ... Anxiety	0=No, 1=Yes	Q1 4.13
AdultIssueNotRel3	Not related to SM I have ... An eating disorder	0=No, 1=Yes	Q1 4.13
AdultIssueNotRel4	Not related to SM I have ... Panic disorder	0=No, 1=Yes	Q1 4.13
AdultIssueNotRel5	Not related to SM I have ... Social phobia / social anxiety	0=No, 1=Yes	Q1 4.13
AdultIssueNotRel6	Not related to SM I have ... Agoraphobia	0=No, 1=Yes	Q1 4.13
AdultIssueNotRel7	Not related to SM I have ... Separation anxiety	0=No, 1=Yes	Q1 4.13
AdultIssueNotRel8	Not related to SM I have ... OCD	0=No, 1=Yes	Q1 4.13
AdultIssueNotRel9	Not related to SM I have ... Post-traumatic stress disorder	0=No, 1=Yes	Q1 4.13
AdultIssueNotRel10	Not related to SM I have ... (Other)	0=No, 1=Yes	Q1 4.13
WhatCouldHaveHelped1	What could have helped? Nothing	0=No, 1=Yes	Q1 4.7
WhatCouldHaveHelped2	What could have helped? Better understanding of SM in the school system	0=No, 1=Yes	Q1 4.7
WhatCouldHaveHelped3	What could have helped? Better professional understanding of SM	0=No, 1=Yes	Q1 4.7
WhatCouldHaveHelped4	What could have helped? Medication in childhood	0=No, 1=Yes	Q1 4.7
WhatCouldHaveHelped5	What could have helped? Tough love / being forced to speak by my parents	0=No, 1=Yes	Q1 4.7
WhatCouldHaveHelped6	What could have helped? Speech therapy	0=No, 1=Yes	Q1 4.7
WhatCouldHaveHelped7	What could have helped? Counselling or CBT in childhood	0=No, 1=Yes	Q1 4.7

WhatCouldHaveHelped8	What could have helped? (Other)	0=No, 1=Yes	Q1 4.7
WhoHelped1	I received effective professional support, which helped me [at least a little bit]	0=No, 1=Yes	Q1 5.1
WhoHelped2	I received professional support which was ineffective	0=No, 1=Yes	Q1 5.1
WhoHelped3	I received professional "support" which was detrimental	0=No, 1=Yes	Q1 5.1
WhoHelped4	My parents / relatives did help me	0=No, 1=Yes	Q1 5.1
WhoHelped5	My parents / relatives tried to help me but didn't know how to, or they weren't able to	0=No, 1=Yes	Q1 5.1
WhoHelped6	My parents made the problem worse	0=No, 1=Yes	Q1 5.1
WhoHelped7	My other relatives made the problem worse	0=No, 1=Yes	Q1 5.1
WhoHelped8	My friends helped me	0=No, 1=Yes	Q1 5.1
WhoHelped9	My friends tried to help me but they didn't know how to, or they weren't able to	0=No, 1=Yes	Q1 5.1
WhoHelped10	Teachers etc. helped me	0=No, 1=Yes	Q1 5.1
WhoHelped11	Teachers etc. tried to help me but they didn't know how to, or they weren't able to	0=No, 1=Yes	Q1 5.1
WhoHelped12	Teachers etc. made the problem worse	0=No, 1=Yes	Q1 5.1
WhoHelped13	Nobody helped me	0=No, 1=Yes	Q1 5.1
WhoHelped14	Others helped me	0=No, 1=Yes	Q1 5.1
ParentHelp	In childhood my parents ...	0=Did not know of my SM, 1=Knew of my SM and sought help, 2=Knew (other) and sought help, 3= Knew of my SM and did not seek help, 4=Knew (other) and did not seek help, 5=Were part of the problem,	Q1 5.2

		6=I don't wish to say 7=Other	
AdultHelp	In adulthood ...	0=I have not sought help, 1=I found effective help, 2=Helpers have been ineffective 3=I don't wish to say, 4=Other	Q1 5.3
SMSev1	SM severity (age <5)	0..10	Q1 2.9
SMSev2	SM severity (age 5-8)	0..10	Q1 2.9
SMSev3	SM severity (age 9-11)	0..10	Q1 2.9
SMSev4	SM severity (age 12-15)	0..10	Q1 2.9
SMSev5	SM severity (age 16-19)	0..10	Q1 2.9
SMSev6	SM severity (age 20-24)	0..10	Q1 2.9
SMSev7	SM severity (age 25-29)	0..10	Q1 2.9
SMSev8	SM severity (age 30-34)	0..10	Q1 2.9
SMSev9	SM severity (age 35-39)	0..10	Q1 2.9
SMSev10	SM severity (age 40-44)	0..10	Q1 2.9
SMSev11	SM severity (age 45-49)	0..10	Q1 2.9
SMSev12	SM severity (age 50-54)	0..10	Q1 2.9
SMSev13	SM severity (age 55-59)	0..10	Q1 2.9
SMSev14	SM severity (age 60+)	0..10	Q1 2.9
ShySev1	Shyness severity (age <5)	0..10	Q2 2.1
ShySev2	Shyness severity (5-8)	0..10	Q2 2.1
ShySev3	Shyness severity (9-11)	0..10	Q2 2.1
ShySev4	Shyness severity (12-15)	0..10	Q2 2.1
ShySev5	Shyness severity (16-19)	0..10	Q2 2.1
ShySev6	Shyness severity (20-24)	0..10	Q2 2.1
ShySev7	Shyness severity (25-29)	0..10	Q2 2.1
ShySev8	Shyness severity (30-34)	0..10	Q2 2.1
ShySev9	Shyness severity (35-39)	0..10	Q2 2.1
ShySev10	Shyness severity (40-44)	0..10	Q2 2.1
ShySev11	Shyness severity (45-49)	0..10	Q2 2.1
ShySev12	Shyness severity (50-54)	0..10	Q2 2.1
ShySev13	Shyness severity (55-59)	0..10	Q2 2.1
ShySev14	Shyness severity (60+)	0..10	Q2 2.1

SPSev1	Social phobia severity (age <5)	0..10	Q2 3.1
SPSev2	Social phobia severity (5-8)	0..10	Q2 3.1
SPSev3	Social phobia severity (9-11)	0..10	Q2 3.1
SPSev4	Social phobia severity (12-15)	0..10	Q2 3.1
SPSev5	Social phobia severity (16-19)	0..10	Q2 3.1
SPSev6	Social phobia severity (20-24)	0..10	Q2 3.1
SPSev7	Social phobia severity (25-29)	0..10	Q2 3.1
SPSev8	Social phobia severity (30-34)	0..10	Q2 3.1
SPSev9	Social phobia severity (35-39)	0..10	Q2 3.1
SPSev10	Social phobia severity (40-44)	0..10	Q2 3.1
SPSev11	Social phobia severity (45-49)	0..10	Q2 3.1
SPSev12	Social phobia severity (50-54)	0..10	Q2 3.1
SPSev13	Social phobia severity (55-59)	0..10	Q2 3.1
SPSev14	Social phobia severity (60+)	0..10	Q2 3.1
SMIsRelated	SM is related to other conditions	0=No, 1=Yes	Q2 4.1
FOSI10	First-order speech inhibition (age 10)	0=No, 1=Yes	COMPUTE FOSI10= Age10SP4|Age10SP5|Age10SP6|Age10SP7|Age10SP8|Age10SP9
SOSI10	Second-order speech inhibition (age 10)	0=No, 1=Yes	COMPUTE SOSI10= Age10SP12|Age10SP13|Age10SP14|Age10SP11|Age10SP10|Age10SP15
TOSI10	Third-order speech inhibition (age 10)	0=No, 1=Yes	COMPUTE TOSI10= Age10SP1|Age10SP20|Age10SP19
OTSI10	Other speech inhibition (age 10)	0=No, 1=Yes	COMPUTE OTSI10= Age10SP3|Age10SP16|Age10SP17|Age10SP18
FOSI18	First-order speech inhibition (age 18)	0=No, 1=Yes	COMPUTE FOSI18= Age18SP4|Age18SP5|Age15SP6|Age18SP7|Age18SP8|Age18SP9

SOSI18	Second-order speech inhibition (age 18)	0=No, 1=Yes	COMPUTE SOSI18= Age18SP12|Age18SP13|Age18SP14|Age18SP11|Age18SP10|Age18SP15
TOSI18	Third-order speech inhibition (age 18)	0=No, 1=Yes	COMPUTE TOSI18= AGE18SP1|Age18SP20|Age18SP19
OTSI18	Other speech inhibition (age 18)	0=No, 1=Yes	COMPUTE OTSI18= AGE18SP3|Age18SP16|Age18SP17|Age18SP18
FOSINow	First-order speech inhibition (now)	0=No, 1=Yes	COMPUTE FOSINow= NowSP4|NowSP5|NowSP6|NowSP7|NowSP8|NowSP9
SOSINow	Second-order speech inhibition (now)	0=No, 1=Yes	COMPUTE SOSINow= NowSP12|NowSP13|NowSP14|NowSP11|NowSP10|NowSP15
TOSINow	Third-order speech inhibition (now)	0=No, 1=Yes	COMPUTE TOSINow= NowSP1|NowSP19
OTSINow	Other speech inhibition (now)	0=No, 1=Yes	COMPUTE OTSINow= NowSP3|NowSP16|NowSP17|NowSP18
FOSIAny	Mute with any first-order	0=No, 1=Yes	COMPUTE FOSIAny= FOSI10|FOSI18|FOSINow
SOSIAny	Mute with any second-order	0=No, 1=Yes	COMPUTE SOSIAny= SOSI10|SOSI18|SOSINow
TOSIAny	Mute with any third-order	0=No, 1=Yes	COMPUTE TOSIANY= TOSI10|TOSI18|TOSINow
OTSIAny	Mute with any other	0=No, 1=Yes	COMPUTE OTSIAny= OTSI10|OTSI18|OTSINow
FOSIPerm	The permutation of ages at which a participant was mute with any first-order	0=N/A, 1=age 10, 2=age 18, 3=age 10 and 18, 4=now, 5=age 10 and now, 6=age 18 and now, 7=age 10, age 18 and now	COMPUTE FOSIPerm= (FOSI10)+(FOSI18*2)+(FOSINow*4)
SOSIPerm	The permutation of ages at which a participant was mute with any second-order	0=N/A, 1=age 10, 2=age 18, 3=age 10 and 18, 4=now, 5=age 10 and now, 6=age 18 and now, 7=age 10, age 18 and now	COMPUTE SOSIPerm= (SOSI10)+(SOSI18*2)+(SOSINow*4)
TOSIPerm	The permutation of ages at which a participant was mute with any third-order	0=N/A, 1=age 10, 2=age 18, 3=age 10 and 18, 4=now, 5=age 10 and now, 6=age 18 and now, 7=age 10, age 18 and now	COMPUTE TOSIPerm= (TOSI10)+(TOSI18*2)+(TOSINow*4)
OTSIPerm	The permutation of ages at which a participant was mute with anyone else	0=N/A, 1=age 10, 2=age 18, 3=age 10 and 18, 4=now, 5=age 10 and now, 6=age 18 and now, 7=age 10, age 18 and now	COMPUTE OTSIPerm= (OTSI10)+(OTSI18*2)+(OTSINow*4)

AnyPerm	The permutation of ages at which a participant was mute with anyone (first-order, second-order, third-order, or other)	0=N/A, 1=age 10, 2=age 18, 3=age 10 and 18, 4=now, 5=age 10 and now, 6=age 18 and now, 7=age 10, age 18 and now	COMPUTE AnyPerm= (FOSI10|SOSI10|TOSI10|OTSI10)+ ((FOSI18|SOSI18|TOSI18|OTS18)*2)+ ((FOSINow|SOSINow|TOSINow|OTSINow)*4)
RelTOT	Sum of all relative situations (first-order and second-order)	0..36	COMPUTE RelTot= Age10SP4+Age18SP4+NowSP4+Age10SP5+Age18SP5+NowSP5+Age10SP6+Age18SP6+NowSP6+Age10SP7+Age18SP7+NewSP7+Age10SP8+Age18SP8+NowSP8+Age10SP9+Age18SP9+NowSP9+Age10SP12+Age18SP12+NowSP12+Age10SP13+Age18SP13+NowSP13+Age10SP14+Age18SP14+NowSP14+Age10SP11+Age18SP11+NowSP11+Age10SP10+Age18SP10+NowSP10+Age10SP15+Age18SP15+NowSP15
OthTOT	Sum of all other situations (third-order and other)	0..21	COMPUTE OthTot= Age10SP1+Age18SP1+NowSP1+Age10SP20+Age18SP20+NowSP20+Age10SP19+Age18SP19+NowSP19+Age10SP3+Age18SP3+NowSP3+Age10SP16+Age18SP16+NowSP16+Age10SP17+Age18SP17+NowSP17+Age10SP18+Age18SP18+NowSP18
CouldntSpeak	Couldn't speak	0=No, 1=Yes	(Thematic analysis)
DidntSpeak	Didn't speak	0=No, 1=Yes	(Thematic analysis)
OthersSaidDidntSpeak	Others said didn't speak	0=No, 1=Yes	(Thematic analysis)
HadFearOfSpeaking	Had fear of speaking	0=No, 1=Yes	(Thematic analysis)
YoungerFemale	Whether a younger female	0=No, 1=Yes	COMPUTE YoungerFemale= (Gender=0)&(YoungerThanAverage=1)
OlderFemale	Whether an older female	0=No, 1=Yes	COMPUTE OlderFemale= (Gender=0)&(YoungerThanAverage=0)
YoungerMale	Whether a younger male	0=No, 1=Yes	COMPUTE YoungerMale= (Gender=1)&(YoungerThanAverage=1)
OlderMale	Whether an older male	0=No, 1=Yes	COMPUTE OlderMale= (Gender=1)&(YoungerThanAverage=0)
ParticipantType	The participant type	0=Younger female, 1=Younger male, 2=Older female, 3=Older male	COMPUTE ParticipantType= (YoungerMale)+(OlderFemale*2)+(OlderMale*3)
AbuseWithinTheHome	Experienced some form of abuse within the home	0=No, 1=Yes	(Thematic analysis)
AbuseBoth	Experienced abuse in both situations (possibly)	0=No, 1=Yes	(Thematic analysis)
AbuseDefOutsideTheHome	Experienced some form of abuse definitely outside the home	0=No, 1=Yes	(Thematic analysis)
AbuseNotExperienced	Did not experience abuse or bullying	0=No, 1=Yes	(Thematic analysis)
AbuseLocation	Abuse location	{0, Home only}...	(Thematic analysis)

DomesticViolence	Witnessing domestic violence	0=No, 1=Yes	(Thematic analysis)
AbusiveFamilyNotSpecified	Whether abusive family	0=No, 1=Yes	(Thematic analysis)
AbusiveFather	Abusive father	0=No, 1=Yes	(Thematic analysis)
AbusiveMother	Abusive mother	0=No, 1=Yes	(Thematic analysis)
AbusiveStepfather	Abusive stepfather	0=No, 1=Yes	(Thematic analysis)
AbusiveTeacher	Abusive teacher	0=No, 1=Yes	(Thematic analysis)
ShyOrProtectiveParents	Shy parents	0=No, 1=Yes	(Thematic analysis)
SexualAssault	Sexual assault	0=No, 1=Yes	(Thematic analysis)
RelShyAndSM	The relationship between Shyness and Selective Mutism	0=SM is the same as shyness, 1=Shyness develops into SM, 2=SM is different than shyness	Q2 2.2
ShynessIsSM	SM is the same as shyness	0=No, 1=Yes	COMPUTE ShynessIsSM= (RelShyAndSM=0).
ShynessDevelopsIntoSM	Shyness develops into SM	0=No, 1=Yes	COMPUTE ShynessDevelopsIntoSM= (RelShyAndSM=1).
ShynessDifferentThanSM	Shyness is different to SM	0=No, 1=Yes	COMPUTE ShynessDifferentThanSM= (RelShyAndSM=2).
RelSPAndSM	The relationship between Social Phobia / Social Anxiety and Selective Mutism	0=SM is the same as SP, 1=SM develops into SP, 2=SM is comorbid with SP, 3=SM is different than SP	Q2 3.1
SMisSA	SM is a form of SP	0=No, 1=Yes	Q1 2.11
SMFormOfSA	SM is a form of SP	0=No, 1=Yes	(Thematic analysis)
SMSameAsSA	SM is the same as SP	0=No, 1=Yes	COMPUTE SMSameAsSA= (RelSPAndSM=0).
SMDevelopsIntoSA	SM develops into SP	0=No, 1=Yes	COMPUTE SMDevelopsIntoSA= (RelSPAndSM=1).
SMComorbidWithSA	SM is comorbid with SP	0=No, 1=Yes	COMPUTE SMComorbidWithSA= (RelSPAndSM=2).
SMDifferentThanSA	SM is different than SP	0=No, 1=Yes	COMPUTE SMDifferentThanSA=(RelSPAndSM=3).
SPDelta1	Difference between SP and SM at age group <5	-10..10	COMPUTE SPDelta1 =SPSev1-SMSev1.
SPDelta2	Difference between SP and SM at age group 5-8	-10..10	COMPUTE SPDelta2 =SPSev2-SMSev2.
SPDelta3	Difference between SP and SM at age group 9-11	-10..10	COMPUTE SPDelta3 =SPSev3-SMSev3.

SPDelta4	Difference between SP and SM at age group 12-15	-10..10	COMPUTE SPDelta4 =SPSev4-SMSev4.
SPDelta5	Difference between SP and SM at age group 16-19	-10..10	COMPUTE SPDelta5 =SPSev5-SMSev5.
SPDelta6	Difference between SP and SM at age group 20-24	-10..10	COMPUTE SPDelta6 =SPSev6-SMSev6.
SPDelta7	Difference between SP and SM at age group 25-29	-10..10	COMPUTE SPDelta7 =SPSev7-SMSev7.
SPDelta8	Difference between SP and SM at age group 30-34	-10..10	COMPUTE SPDelta8 =SPSev8-SMSev8.
SPDelta9	Difference between SP and SM at age group 35-39	-10..10	COMPUTE SPDelta9 =SPSev9-SMSev9.
SPDelta10	Difference between SP and SM at age group 40-44	-10..10	COMPUTE SPDelta10 =SPSev10-SMSev10.
SPDelta11	Difference between SP and SM at age group 45-49	-10..10	COMPUTE SPDelta11 =SPSev11-SMSev11.
SPDelta12	Difference between SP and SM at age group 50-54	-10..10	COMPUTE SPDelta12 =SPSev12-SMSev12.
SPDelta13	Difference between SP and SM at age group 55-59	-10..10	COMPUTE SPDelta13 =SPSev13-SMSev13.
SPDelta14	Difference between SP and SM at age group 60+	-10..10	COMPUTE SPDelta14 =SPSev14-SMSev14.
ShyDelta1	Difference between shyness and SM at age group <5	-10..10	COMPUTE ShyDelta1 =ShySev1-SMSev1.
ShyDelta2	Difference between shyness and SM at age group 5-8	-10..10	COMPUTE ShyDelta2 =ShySev2-SMSev2.
ShyDelta3	Difference between shyness and SM at age group 9-11	-10..10	COMPUTE ShyDelta3 =ShySev3-SMSev3.
ShyDelta4	Difference between shyness and SM at age group 12-15	-10..10	COMPUTE ShyDelta4= ShySev4-SMSev4.
ShyDelta5	Difference between shyness and SM at age group 16-19	-10..10	COMPUTE ShyDelta5= ShySev5-SMSev5.
ShyDelta6	Difference between shyness and SM at age group 20-24	-10..10	COMPUTE ShyDelta6= ShySev6-SMSev6.
ShyDelta7	Difference between shyness and SM at age group 25-29	-10..10	COMPUTE ShyDelta7= ShySev7-SMSev7.
ShyDelta8	Difference between shyness and SM at age group 30-34	-10..10	COMPUTE ShyDelta8= ShySev8-SMSev8.

ShyDelta9	Difference between shyness and SM at age group 35-39	-10..10	COMPUTE ShyDelta9= ShySev9-SMSev9.
ShyDelta10	Difference between shyness and SM at age group 40-44	-10..10	COMPUTE ShyDelta10= ShySev10-SMSev10.
ShyDelta11	Difference between shyness and SM at age group 45-49	-10..10	COMPUTE ShyDelta11= ShySev11-SMSev11.
ShyDelta12	Difference between shyness and SM at age group 50-54	-10..10	COMPUTE ShyDelta12= ShySev12-SMSev12.
ShyDelta13	Difference between shyness and SM at age group 55-59	-10..10	COMPUTE ShyDelta13= ShySev13-SMSev13.
ShyDelta14	Difference between shyness and SM at age group 60+	-10..10	COMPUTE ShyDelta14= ShySev14-SMSev14.
SPDeltaTOT	Total difference between SP and SM for age 5-24.	-10..10	COMPUTE SPDeltaTOT= SPDelta2+SPDelta3+SPDelta4+SPDelta5+SPDelta6.
ShyDeltaTOT	Total difference between SP and SM for ages 5-24.	-10..10	COMPUTE ShyDeltaTOT= ShyDelta2+ShyDelta3+ShyDelta4+ShyDelta5+ ShyDelta6.
MoreSPThanSM	Whether the participant had more SP than SM between ages 5-24.	0=No, 1=Yes	COMPUTE MoreSPThanSM= (SPDeltaTOT>=0).
MoreShyThanSM	Whether the participant had more SM than SP between ages 5-24.	0=No, 1=Yes	COMPUTE MoreShyThanSM= (ShyDeltaTOT>=0).
MoreSP1	Whether more SP than SM at age group <5	0=No, 1=Yes	COMPUTE MoreSP1= (SPDelta1>=0).
MoreSP2	Whether more SP than SM at age group 5-8	0=No, 1=Yes	COMPUTE MoreSP2= (SPDelta2>=0).
MoreSP3	Whether more SP than SM at age group 9-11	0=No, 1=Yes	COMPUTE MoreSP3= (SPDelta3>=0).
MoreSP4	Whether more SP than SM at age group 12-15	0=No, 1=Yes	COMPUTE MoreSP4= (SPDelta4>=0).
MoreSP5	Whether more SP than SM at age group 16-19	0=No, 1=Yes	COMPUTE MoreSP5= (SPDelta5>=0).
MoreSP6	Whether more SP than SM at age group 20-24	0=No, 1=Yes	COMPUTE MoreSP6= (SPDelta6>=0).
MoreSP7	Whether more SP than SM at age group 25-29	0=No, 1=Yes	COMPUTE MoreSP7= (SPDelta7>=0).
MoreSP8	Whether more SP than SM at age group 30-34	0=No, 1=Yes	COMPUTE MoreSP8= (SPDelta8>=0).

MoreSP9	Whether more SP than SM at age group 35-39	0=No, 1=Yes	COMPUTE MoreSP9= (SPDelta9>=0).
MoreSP10	Whether more SP than SM at age group 40-44	0=No, 1=Yes	COMPUTE MoreSP10= (SPDelta10>=0).
MoreSP11	Whether more SP than SM at age group 45-49	0=No, 1=Yes	COMPUTE MoreSP11= (SPDelta11>=0).
MoreSP12	Whether more SP than SM at age group 50-54	0=No, 1=Yes	COMPUTE MoreSP12= (SPDelta12>=0).
MoreSP13	Whether more SP than SM at age group 55-59	0=No, 1=Yes	COMPUTE MoreSP13= (SPDelta13>=0).
MoreSP14	Whether more SP than SM at age group 60+	0=No, 1=Yes	COMPUTE MoreSP14= (SPDelta14>=0).
MoreSPAny	Whether more SP than SM at any age group	0=No, 1=Yes	COMPUTE MoreSPAny= MoreSP1|MoreSP2|MoreSP3|MoreSP4|MoreSP5|MoreSP6|MoreSP7|MoreSP8|MoreSP9|MoreSP10|MoreSP11|MoreSP12|MoreSP13|MoreSP14
MoreSMAny	Whether more SM than SP at any age group	0=No, 1=Yes	COMPUTE MoreSMAny= ~MoreSP1|~MoreSP2|~MoreSP3|~MoreSP4|~MoreSP5|~MoreSP6|~MoreSP7|~MoreSP8|~MoreSP9|~MoreSP10|~MoreSP11|~MoreSP12|~MoreSP13|~MoreSP14

Appendix F. SPSS scripts used in the quantitative analyses

The following tables lists every SPSS script used to generate a table or figure. The meaning of each SPSS variable thus source in each questionnaire can be discerned by referring back to Appendix E.

Table 39 — SPSS scripts used in the quantitative analyses

Table or figure (page)	**SPSS Script**
Table 6 — Recovery rates of participants by gender (p. 49)	CROSSTABS /TABLES=Gender BY Recovered /FORMAT=AVALUE TABLES /CELLS=COUNT TOTAL /COUNT ROUND CELL.
Table 7 — Gender and age-ranges of participants (p. 49)	MEANS TABLES=Age BY Gender /CELLS MEAN COUNT STDDEV MIN MAX.
Table 8 — Frequency of participants per age-group by gender (p. 49)	CROSSTABS /TABLES=Gender BY AgeGroup /FORMAT=AVALUE TABLES /CELLS=COUNT TOTAL /COUNT ROUND CELL.
Table 9 — Key ages (p. 50)	T-TEST GROUPS=Gender(0 1) /MISSING=ANALYSIS /VARIABLES=AgeOfOnset AgeOfRealization RecoveryAge ImprovementAge AgeKnownCond /CRITERIA=CI(.95).
Figure 1 — Age of onset age-range frequencies (p. 51)	FREQUENCIES VARIABLES=AgeOfOnsetRange /ORDER=ANALYSIS.
Table 10 — How adults with SM realized there was a name for their condition (p. 51)	FREQUENCIES VARIABLES=Discovery /ORDER=ANALYSIS.
Table 11 — *t-test* between reported severities of those who received a diagnosis of SM in childhood and those who did not (p. 52)	T-TEST GROUPS=Diagnosed(0 1) /MISSING=ANALYSIS /VARIABLES=SMSev1 SMSev2 SMSev3 SMSev4 SMSev5 SMSev6 SMSev7 SMSev8 SMSev9 SMSev10 SMSev11 SMSev12 SMSev13 SMSev14 /CRITERIA=CI(.95).
Table 12 — Conditions comorbid with SM in childhood and adulthood (p. 53)	FREQUENCIES VARIABLES=ChildIssue1 ChildIssue2 ChildIssue3 ChildIssue4 ChildIssue5 ChildIssue6 ChildIssue7 ChildIssue8 ChildIssue9 ChildIssue10 AdultIssue1 AdultIssue2 AdultIssue3 AdultIssue4 AdultIssue5 AdultIssue6 AdultIssue7 AdultIssue8 AdultIssue9 AdultIssue10 AdultIssueRel1 AdultIssueRel2 AdultIssueRel3 AdultIssueRel4 AdultIssueRel5 AdultIssueRel6 AdultIssueRel7 AdultIssueRel8 AdultIssueRel9 AdultIssueRel10 AdultIssueNotRel1 AdultIssueNotRel2 AdultIssueNotRel3 AdultIssueNotRel4 AdultIssueNotRel5 AdultIssueNotRel6 AdultIssueNotRel7 AdultIssueNotRel8 AdultIssueNotRel9 AdultIssueNotRel10 /NTILES=20 /ORDER=ANALYSIS.
Table 13 — Rates of mental health conditions in adults with SM vs. the general population (p. 55)	(Using data from PS7112_Data_Actual_Expected_ChiSq.sav rather than PS7112_Data.sav) WEIGHT BY DepFem. NPAR TESTS /CHISQUARE=DepFem /EXPECTED=7.68 58.32 /MISSING ANALYSIS. WEIGHT BY DepMal. NPAR TESTS /CHISQUARE=DepMal /EXPECTED=1.75 15.25 /MISSING=ANALYSIS. WEIGHT BY AnxFem. NPAR TESTS /CHISQUARE=AnxFem /EXPECTED=6.13 59.87 /MISSING=ANALYSIS.

	WEIGHT BY AnxMal. NPAR TESTS /CHISQUARE=AnxMal /EXPECTED=1.33 15.67 /MISSING=ANALYSIS. WEIGHT BY EatFem. NPAR TESTS /CHISQUARE=EatFem /EXPECTED=6.07 59.93 /MISSING=ANALYSIS. WEIGHT BY EatMal. NPAR TESTS /CHISQUARE=EatMal /EXPECTED=0.60 16.40 /MISSING=ANALYSIS. WEIGHT BY PanDisFem. NPAR TESTS /CHISQUARE=PanDisFem /EXPECTED=1.35 64.65 /MISSIGN=ANALYSIS. WEIGHT BY PanDisMal. NPAR TESTS /CHISQUARE=PanDisMal /EXPECTED=0.33 16.67 /MISSING=ANALYSIS. WEIGHT BY SocAnx. NPAR TESTS /CHISQUARE=SocAnx /EXPECTED=4.15 78.85 /MISSING=ANALYSIS. WEIGHT BY OCD. NPAR TESTS /CHISQUARE=OCR /EXPECTED=2.08 80.92 /MISSING=ANALYSIS. WEIGHT BY PTSDFem. NPAR TESTS /CHISQUARE=PTSDFem /EXPECTED=2.18 63.82 /MISSING=ANALYSIS. WEIGHT BY PTSDMal. NPAR TESTS /CHISQUARE=PTSDMal /EXPECTED=0.44 16.56 /MISSING=ANALYSIS.
Figure 2 — Responses to whether outcomes related to SM could have been avoided (p. 56)	FREQUENCIES VARIABLES=CouldHaveAvoided /ORDER=ANALYSIS.
Figure 3 — Responses to "what could have helped in childhood?" (p. 57)	FREQUENCIES VARIABLES=WhatCouldHaveHelped1 WhatCouldHaveHelped2 WhatCouldHaveHelped3 WhatCouldHaveHelped4 WhatCouldHaveHelped5 WhatCouldHaveHelped6 WhatCouldHaveHelped7 WhatCouldHaveHelped8 /ORDER=ANALYSIS.
Figure 4 — Responses to "who helped you?" (p. 57)	FREQUENCIES VARIABLES=WhoHelped1 WhoHelped2 WhoHelped3 WhoHelped4 WhoHelped5 WhoHelped6 WhoHelped7 WhoHelped8 WhoHelped9 WhoHelped10 WhoHelped11 WhoHelped12 WhoHelped13 WhoHelped14 ParentHelp /ORDER=ANALYSIS.
Table 14 — Age group differences regarding "who helped you?" (p. 58)	CROSSTABS /TABLES=YoungerThanAverage BY WhoHelped1 WhoHelped2 WhoHelped3 WhoHelped4 WhoHelped5 WhoHelped6 WhoHelped7 WhoHelped8 WhoHelped9 WhoHelped10 WhoHelped11 WhoHelped12 WhoHelped13 WhoHelped14 /FORMAT=AVALUE TABLES /STATISTICS=CHISQ CORR /CELLS=COUNT /COUNT ROUND CELL.
Table 15 — Self-reported SM severity by age (p. 59)	T-TEST /TESTVAL=5 /MISSING=ANALYSIS /VARIABLES=SMSev1 SMSev2 SMSev3 SMSev4 SMSev5 SMSev6 SMSev7 SMSev8 SMSev9 SMSev10 SMSev11 SMSev12 SMSev13 SMSev14 /CRITERIA=CI(.95). T-TEST GROUPS=Gender(0 1) /MISSING=ANALYSIS /VARIABLES=SMSev1 SMSev2 SMSev3 SMSev4 SMSev5 SMSev6 SMSev7 SMSev8 SMSev9 SMSev10 SMSev11 SMSev12 SMSev13 SMSev14 /CRITERIA=CI(.95). T-TEST GROUPS=YoungerThanAverage(0 1) /MISSING=ANALYSIS /VARIABLES=SMSev1 SMSev2 SMSev3 SMSev4 SMSev5 SMSev6 SMSev7 SMSev8 SMSev9 SMSev10 SMSev11 SMSev12 SMSev13 SMSev14 /CRITERIA=CI(.95).
Table 16 — Speech pattern distribution (situations in which muteness occurred) (p. 60)	FREQUENCIES VARIABLES=FOSI10 SOSI10 TOSI10 OTSI10 FOSI18 SOSI18 TOSI18 OTSI18 FOSINow SOSINow TOSINow OTSINow FOSIAny SOSIAny TOSIAny OTSIAny /ORDER=ANALYSIS.
Figure 5 — Frequencies of speech inhibition by situation (p. 61)	FREQUENCIES VARIABLES=Age10SP4 Age10SP5 Age10SP6 Age10SP7 Age10SP8 Age10SP9 Age10SP12 Age10SP13 Age10SP14 Age10SP11 Age10SP10 Age10SP15 Age10SP1 Age10SP20 Age10SP19 Age10SP3 Age10SP16 Age10SP17 Age10SP18 Age18SP4 Age18SP5 Age18SP6 Age18SP7 Age18SP8 Age18SP9 Age18SP12 Age18SP13 Age18SP14 Age18SP11 Age18SP10 Age18SP15 Age18SP1 Age18SP20 Age18SP19 Age18SP3 Age18SP16 Age18SP17 Age18SP18 NowSP4 NowSP5 NowSP6 NowSP7 NowSP8 NowSP9 NowSP12 NowSP13 NowSP14 NowSP11 NowSP10 NowSP15 NowSP1 NowSP19 NowSP3 NowSP16 NowSP17 NowSP18 /ORDER=ANALYSIS.

Table 17 — Changes in speech pattern between 10 to 18 and 18 until now (p. 62)	CROSSTABS /TABLES=FOSI18 SOSI18 TOSI18 OTSI18 BY FOSI10 SOSI10 TOSI10 OTSI10 /FORMAT=AVALUE TABLES /STATISTICS=CHISQ /CELLS=COUNT /COUNT ROUND CELL.
Table 18 — Settings in which muteness occurred vs. age permutations (p. 62)	CROSSTABS /TABLES=FOSIAny SOSIAny TOSIAny OTSIAny BY FOSIPerm SOSIPerm TOSIPerm OTSIPerm AnyPerm /FORMAT=AVALUE TABLES /CELLS=COUNT /COUNT ROUND CELL.
Figure 6 — Scatterplot between familial mutism (mutism with first and second degree relatives) and stranger mutism (mutism with peers and others) (p. 63)	(Scatterplot between RelTOT and OthTOT) CORRELATIONS /VARIABLES=RelTOT OthTOT /PRINT=TWOTAIL NOSIG /MISSING=PAIRWISE. COMPUTE filter_$=(RelTOT>0). FILTER BY filter_$. CORRELATIONS /VARIABLES=RelTOT OthTOT /PRINT=TWOTAIL NOSIG /MISSING=PAIRWISE.
Table 19 — χ2-tests of personal description of SM vs. situation (p. 64)	CROSSTABS /TABLES=FOSIAny SOSIAny TOSIAny OTSIAny BY Describes13 Describes9 Describes7 Describes2 Describes1 Describes8 Describes11 Describes14 Describes17 Describes4 Describes12 Describes15 Describes16 Describes10 Describes3 Describes5 SMisSA /FORMAT=AVALUE TABLES /STATISTICS=CHISQ CORR /CELLS=COUNT /COUNT ROUND CELL.
Figure 7 — How participants describe *their own* SM (p. 66)	FREQUENCIES VARIABLES=Describes13 Describes9 Describes7 Describes2 Describes1 Describes8 Describes11 Describes14 Describes17 Describes4 Describes12 Describes15 Describes16 Describes10 Describes3 Describes5 SMisSA /ORDER=ANALYSIS.
Table 20 — Hierarchical binary logistic regression evaluating predictors of participants saying SM is a form of SP (p. 67)	LOGISTIC REGRESSION VARIABLES SMisSA /METHOD=FSTEP(COND) YoungerThanAverage Gender /METHOD=FSTEP(COND) Describes13 Describes9 Describes7 Describes2 Describes1 Describes8 Describes11 Describes14 Describes17 Describes4 Describes12 Describes15 Describes16 Describes10 Describes3 Describes5 /METHOD=FSTEP(COND) ChildIssue1 ChildIssue2 ChildIssue3 ChildIssue4 ChildIssue5 ChildIssue6 ChildIssue7 ChildIssue8 ChildIssue9 /METHOD=FSTEP(COND) AdultIssue1 AdultIssue2 AdultIssue3 AdultIssue4 AdultIssue5 AdultIssue6 AdultIssue7 AdultIssue8 AdultIssue9 /CONTRAST (YoungerThanAverage)=Indicator(1) /CONTRAST (Gender)=Indicator(1) /CONTRAST (Describes13)=Indicator(1) /CONTRAST (Describes9)=Indicator(1) /CONTRAST (Describes7)=Indicator(1) /CONTRAST (Describes2)=Indicator(1) /CONTRAST (Describes1)=Indicator(1) /CONTRAST (Describes8)=Indicator(1) /CONTRAST (Describes11)=Indicator(1) /CONTRAST (Describes14)=Indicator(1) /CONTRAST (Describes17)=Indicator(1) /CONTRAST (Describes4)=Indicator(1) /CONTRAST (Describes12)=Indicator(1) /CONTRAST (Describes15)=Indicator(1) /CONTRAST (Describes16)=Indicator(1) /CONTRAST (Describes10)=Indicator(1) /CONTRAST (Describes3)=Indicator(1) /CONTRAST (Describes5)=Indicator(1) /CONTRAST (ChildIssue1)=Indicator(1) /CONTRAST (ChildIssue2)=Indicator(1) /CONTRAST (ChildIssue3)=Indicator(1) /CONTRAST (ChildIssue4)=Indicator(1) /CONTRAST (ChildIssue5)=Indicator(1) /CONTRAST (ChildIssue6)=Indicator(1) /CONTRAST (ChildIssue7)=Indicator(1) /CONTRAST (ChildIssue8)=Indicator(1) /CONTRAST (ChildIssue9)=Indicator(1) /CONTRAST (AdultIssue1)=Indicator(1) /CONTRAST (AdultIssue2)=Indicator(1) /CONTRAST (AdultIssue3)=Indicator(1) /CONTRAST (AdultIssue4)=Indicator(1) /CONTRAST (AdultIssue5)=Indicator(1) /CONTRAST (AdultIssue6)=Indicator(1) /CONTRAST (AdultIssue7)=Indicator(1) /CONTRAST (AdultIssue8)=Indicator(1) /CONTRAST (AdultIssue9)=Indicator(1) /CRITERIA=PIN(.05) POUT(.10) ITERATE(20) CUT(.5).
Table 21 — Severities of SM and Social Phobia (p. 69)	DESCRIPTIVES VARIABLES=SMSev1 SMSev2 SMSev3 SMSev4 SMSev5 SMSev6 SMSev7 SMSev8 SMSev9 SMSev10 SMSev11 SMSev12 SMSev13 SMSev14 SPSev1 SPSev2 SPSev3 SPSev4 SPSev5 SPSev6 SPSev7 SPSev8 SPSev9 SPSev10 SPSev11 SPSev12 SPSev13 SPSev14 /STATISTICS=MEAN STDDEV MIN MAX.
Table 22 — Paired-samples *t-tests* and correlations between SM and Social Phobia between "SM is a form of SP" groups (p. 70)	T-TEST PAIRS=SMSev1 SMSev2 SMSev3 SMSev4 SMSev5 SMSev6 SMSev7 SMSev8 SMSev9 SMSev10 SMSev11 SMSev12 SMSev13 SMSev14 WITH SPSev1 SPSev2 SPSev3 SPSev4 SPSev5 SPSev6 SPSev7 SPSev8 SPSev9 SPSev10 SPSev11 SPSev12 SPSev13 SPSev14 (PAIRED) /CRITERIA=CI(.9500) /MISSING=ANALYSIS.
Figure 8 — Plot of SP-SM (difference between SP and SM) for	SPLIT FILE LAYERED BY SMisSA.

those who said “SM is a form of SP” and those who did not (p. 71)	DESCRIPTIVES VARIABLES=SPDelta1 SPDelta2 SPDelta3 SPDelta4 SPDelta5 SPDelta6 SPDelta7 SPDelta8 SPDelta9 SPDelta10 SPDelta11 SPDelta12 SPDelta13 SPDelta14 /STATISTICS=MEAN STDDEV MIN MAX.
Table 23 — Independent samples *t-tests* for SP-SM by age-group between those who said “SM is a form of SP” and those who did not (p. 72)	T-TEST GROUPS=SMisSA(0 1) /MISSING=ANALYSIS /VARIABLES=SPDelta1 SPDelta2 SPDelta3 SPDelta4 SPDelta5 SPDelta6 SPDelta7 SPDelta8 SPDelta9 SPDelta10 SPDelta11 SPDelta12 SPDelta13 SPDelta14 /CRITERIA=CI(.95).
Table 24 — Contrasting SP-SM at age range 5 to 8 with SP-SM at age range 20 to 24 (p. 73)	CROSSTABS /TABLES=MoreSP2 BY MoreSP6 /FORMAT=AVALUE TABLES /STATISTICS=CHISQ CORR /CELLS=COUNT /COUNT ROUND CELL.
Table 25 — Contrasting SP-SM at all ages (p. 74)	CROSSTABS /TABLES=MoreSPAny BY MoreSMAny /FORMAT=AVALUE TABLES /STATISTICS=CHISQ CORR /CELLS=COUNT /COUNT ROUND CELL.
Figure 9 — Triggers and environmental factors and SM (p. 74)	FREQUENCIES VARIABLES=Trigger /ORDER=ANALYSIS.
Table 26 — Experiences of abuse in relation to SM (themes) (p. 75)	FREQUENCIES VARIABLES=AbuseWithinTheHome AbuseBoth AbuseDefOutsideTheHome Because21 DomesticViolence AbusiveFamilyNotSpecified AbusiveFather AbusiveMother AbusiveStepfather AbusiveTeacher SexualAssault /ORDER=ANALYSIS.
Table 27 — Adult and child mental health conditions and SM for those who experienced abuse within the home environment compared to those who did not (p. 76)	CROSSTABS /TABLES=ChildIssue1 ChildIssue2 ChildIssue3 ChildIssue4 ChildIssue5 ChildIssue6 ChildIssue7 ChildIssue8 ChildIssue9 AdultIssue1 AdultIssue2 AdultIssue3 AdultIssue4 AdultIssue5 AdultIssue6 AdultIssue7 AdultIssue8 AdultIssue9 BY AbuseWithinTheHome AbuseDefOutsideTheHome /FORMAT=AVALUE TABLES /STATISTICS=CHISQ CORR /CELLS=COUNT /COUNT ROUND CELL.
Table 28 — Speech pattern and abuse (p. 77)	CROSSTABS /TABLES=AbuseWithinTheHome AbuseBoth AbuseDefOutsideTheHome BY FOSIAny SOSIAny TOSIAny OTSIAny /FORMAT=AVALUE TABLES /STATISTICS=CHISQ CORR /CELLS=COUNT /COUNT ROUND CELL.
Table 29 — Hierarchical binary logistic regression evaluating predictors of muteness with first-order relatives at age 18 (p. 78)	LOGISTIC REGRESSION VARIABLES FOSI18 /METHOD=FSTEP(COND) FOSI10 SOSI10 TOSI10 OTSI10 /METHOD=FSTEP(COND) AbuseWithinTheHome /METHOD=FSTEP(COND) Describes9 /METHOD=FSTEP(COND) Describes13 Describes7 Describes2 Describes1 Describes8 Describes11 Describes14 Describes17 Describes4 Describes12 Describes15 Describes16 Describes10 Describes3 Describes5 /CONTRAST (FOSI10)=Indicator(1) /CONTRAST (SOSI10)=Indicator(1) /CONTRAST (TOSI10)=Indicator(1) /CONTRAST (OTSI10)=Indicator(1) /CONTRAST (AbuseWithinTheHome)=Indicator(1) /CONTRAST (Describes9)=Indicator(1) /CONTRAST (Describes13)=Indicator(1) /CONTRAST (Describes7)=Indicator(1) /CONTRAST (Describes2)=Indicator(1) /CONTRAST (Describes1)=Indicator(1) /CONTRAST (Describes8)=Indicator(1) /CONTRAST (Describes11)=Indicator(1) /CONTRAST (Describes14)=Indicator(1) /CONTRAST (Describes17)=Indicator(1) /CONTRAST (Describes4)=Indicator(1) /CONTRAST (Describes12)=Indicator(1) /CONTRAST (Describes15)=Indicator(1) /CONTRAST (Describes16)=Indicator(1) /CONTRAST (Describes10)=Indicator(1) /CONTRAST (Describes3)=Indicator(1) /CONTRAST (Describes5)=Indicator(1) /CRITERIA=PIN(.05) POUT(.10) ITERATE(20) CUT(.5).
Table 30 — SM severity and abuse within the home (p. 80) Figure 10 — SM severity and abuse within the home (p. 81)	T-TEST GROUPS=AbuseWithinTheHome(0 1) /MISSING=ANALYSIS /VARIABLES=SMSev1 SMSev2 SMSev3 SMSev4 SMSev5 SMSev6 SMSev7 SMSev8 SMSev9 SMSev10 SMSev11 SMSev12 SMSev13 SMSev14 /CRITERIA=CI(.95).
Figure 11 — Participation by country (p. 82)	FREQUENCIES VARIABLES=Country /ORDER=ANALYSIS.
Figure 12 — What participants felt about SM (p. 82)	DESCRIPTIVES VARIABLES=Rating1 Rating2 Rating3 Rating4 Rating5 Rating6 Rating7 Rating8 Rating9 Rating10 Rating11 Rating12 Rating13 Rating14 /STATISTICS=MEAN STDDEV MIN MAX.

Table 31 — Descriptive stats for ANOVA of ratings vs. gender and ratings vs. age category (p. 83) Table 32 — ANOVA of ratings vs. gender and age category (p. 84)	GLM Rating1 Rating2 Rating3 Rating4 Rating5 Rating6 Rating7 Rating8 Rating9 Rating10 Rating11 Rating12 Rating13 Rating14 BY YoungerThanAverage Gender /METHOD=SSTYPE(3) /INTERCEPT=INCLUDE /PLOT=PROFILE(Gender*YoungerThanAverage) /EMMEANS=TABLES(Gender) /EMMEANS=TABLES(YoungerThanAverage) /PRINT=DESCRIPTIVE HOMOGENEITY OPOWER /CRITERIA=ALPHA(.05) /DESIGN= YoungerThanAverage Gender YoungerThanAverage*Gender.
Table 33 — Feelings about SM and abuse (p. 86)	T-TEST GROUPS=AbuseWithinTheHome(0 1) /MISSING=ANALYSIS /VARIABLES=Rating1 Rating2 Rating3 Rating4 Rating5 Rating6 Rating7 Rating8 Rating9 Rating10 Rating11 Rating12 Rating13 Rating14 /CRITERIA=CI(.95).
Figure 13 — Reasons chosen (from those given) for mutism at any stage of the condition (p. 88)	FREQUENCIES VARIABLES=Because1 Because2 Because3 Because4 Because5 Because6 Because7 Because8 Because9 Because10 Because11 Because12 Because13 Because14 Because15 Because16 Because17 Because18 Because19 Because20 Because21 Because22 Because23 Because24 Because25 Because26 Because27 Because28 Because29 Because30 Because31 Because32 Because33 /ORDER=ANALYSIS.
Table 34 — Age and gender differences regarding reasons for mutism (p. 89)	CROSSTABS /TABLES=Because1 Because2 Because3 Because4 Because5 Because6 Because7 Because8 Because9 Because10 Because11 Because12 Because13 Because14 Because15 Because16 Because17 Because18 Because19 Because20 Because21 Because22 Because23 Because24 Because25 Because26 Because27 Because28 Because29 Because30 Because31 Because32 Because33 BY Gender YoungerThanAverage /FORMAT=AVALUE TABLES /STATISTICS=CHISQ CORR /CELLS=COUNT /COUNT ROUND CELL.
Table 40 — Correlation matrix, showing key age relationships (p. 196)	CORRELATIONS /VARIABLES=Age AgeOfOnsetRange AgeOfRealization ImprovementAge RecoveryAge AgeKnownCond /PRINT=TWOTAIL NOSIG /MISSING=PAIRWISE.
Figure 14 — Combined scatterplot of age of improvement and age of knowing SM was a named condition vs. current age (p. 197)	(Scatterplot of ImprovementAge & AgeKnownCond against Age)
Figure 15 — Scatterplot of age of onset vs. age of realization of difference (p. 198)	(Scatterplot of AgeOfRealization against Age)
Figure 16 — Frequencies of ages of realization (p. 199)	FREQUENCIES VARIABLES=AgeOfRealizationGroup /ORDER=ANALYSIS.
Figure 17 — Scatterplot of age of improvement vs. age knew SM was a named condition (p. 199)	(Scatter plot of ImprovementAge against AgeKnownCond)
Table 41 — Percentiles for age of improvement (p. 199)	FREQUENCIES VARIABLES=ImprovementAge /NTILES=20 /ORDER=ANALYSIS.
Table 42 — Contrasting key ages after performing a means split on current age (p. 200)	T-TEST GROUPS=YoungerThanAverage(0 1) /MISSING=ANALYSIS /VARIABLES=AgeOfOnset AgeOfRealization AgeSharedCond ImprovementAge RecoveryAge AgeKnownCond /CRITERIA=CI(.95).
Table 43 — How adults with SM realized their difference (p. 202)	FREQUENCIES VARIABLES=RealizationType /ORDER=ANALYSIS.
Table 44 — Asperger Syndrome vs. autistic traits (p. 203)	CROSSTABS /TABLES=Describes9 BY AspergerSyndrome /FORMAT=AVALUE TABLES /STATISTICS=CHISQ CORR /CELLS=COUNT /COUNT ROUND CELL.
Table 45 — What participants with SM believe their SM to be (p. 204)	CROSSTABS /TABLES=InabilityToSpeak DueToAnxiety DueToFNE WindowToTheSoul FearOfSpeech SubconsciousResponse FreezeResponse Disconnect SlowedThoughts FeelingTrapped ThroatMouthLocked LackOfSocialSkills SelfProtection FeelingIncongruous BY YoungerFemale OlderFemale YoungerMale OlderMale /FORMAT=AVALUE TABLES /STATISTICS=CHISQ CORR /CELLS=COUNT /COUNT ROUND CELL

Table 46 — How adults recovered from SM or partially improved (p. 205)	(Thematic analysis)
Figure 18 — Responses to "in childhood, my parents…" regarding seeking help (p. 207)	FREQUENCIES VARIABLES=ParentHelp /ORDER=ANALYSIS.
Figure 19 — Responses to "in adulthood…" regarding professional help (p. 208)	FREQUENCIES VARIABLES=AdultHelp /ORDER=ANALYSIS.
Figure 20 — Relationship between SM and Shyness (p. 208)	FREQUENCIES VARIABLES=RelShyAndSM /ORDER=ANALYSIS.
Table 47 — Severities of SM and Shyness (p. 209)	DESCRIPTIVES VARIABLES=SMSev1 SMSev2 SMSev3 SMSev4 SMSev5 SMSev6 SMSev7 SMSev8 SMSev9 SMSev10 SMSev11 SMSev12 SMSev13 SMSev14 ShySev1 ShySev2 ShySev3 ShySev4 ShySev5 ShySev6 ShySev7 ShySev8 ShySev9 ShySev10 ShySev11 ShySev12 ShySev13 ShySev14 /STATISTICS=MEAN STDDEV MIN MAX.

Appendix G. Ancillary results

This section includes results which are not necessary for the main body of text, which are nonetheless interesting to report.

A correlation matrix between key ages is shown in Table 40 for all participants, and includes those who had recovered.

Table 40 — Correlation matrix, showing key age relationships

		Current age	**Age of onset**	**Realization of difference**	**Age of improvement**	**Age of recovery**
Current age	**Correlation** **Sig** **N**	-				
Age of onset	**Correlation** **Sig** **N**	-0.05† .70 69	-			
Realization of difference	**Correlation** **Sig** **N**	0.18 .10 83	0.32** <.01 69	-		
Age of improvement	**Correlation** **Sig** **N**	0.69*** <.001 58	0.16 .26 50	0.11 .42 58	-	
Age of recovery	**Correlation** **Sig** **N**	0.83 .17 4	-1.00** 2	0.03 .97 4	 1	-
Knew SM was named cond.	**Correlation** **Sig** **N**	0.84*** <.001 83	0.02 .85 69	0.21 .06 83	0.59*** <.001 58	0.16 .84 4

The orthogonality between age at the time of participating and age of onset is precisely as expected (†), and serves to validate the data, in that participants usually developed their condition (SM) before age 5 (usually prior to ordinary childhood amnesia), as expected. This is irrespective of their current age. There are a number of significant Pearson's correlations shown in the correlation matrix, which are indicated in the following scatter plots.

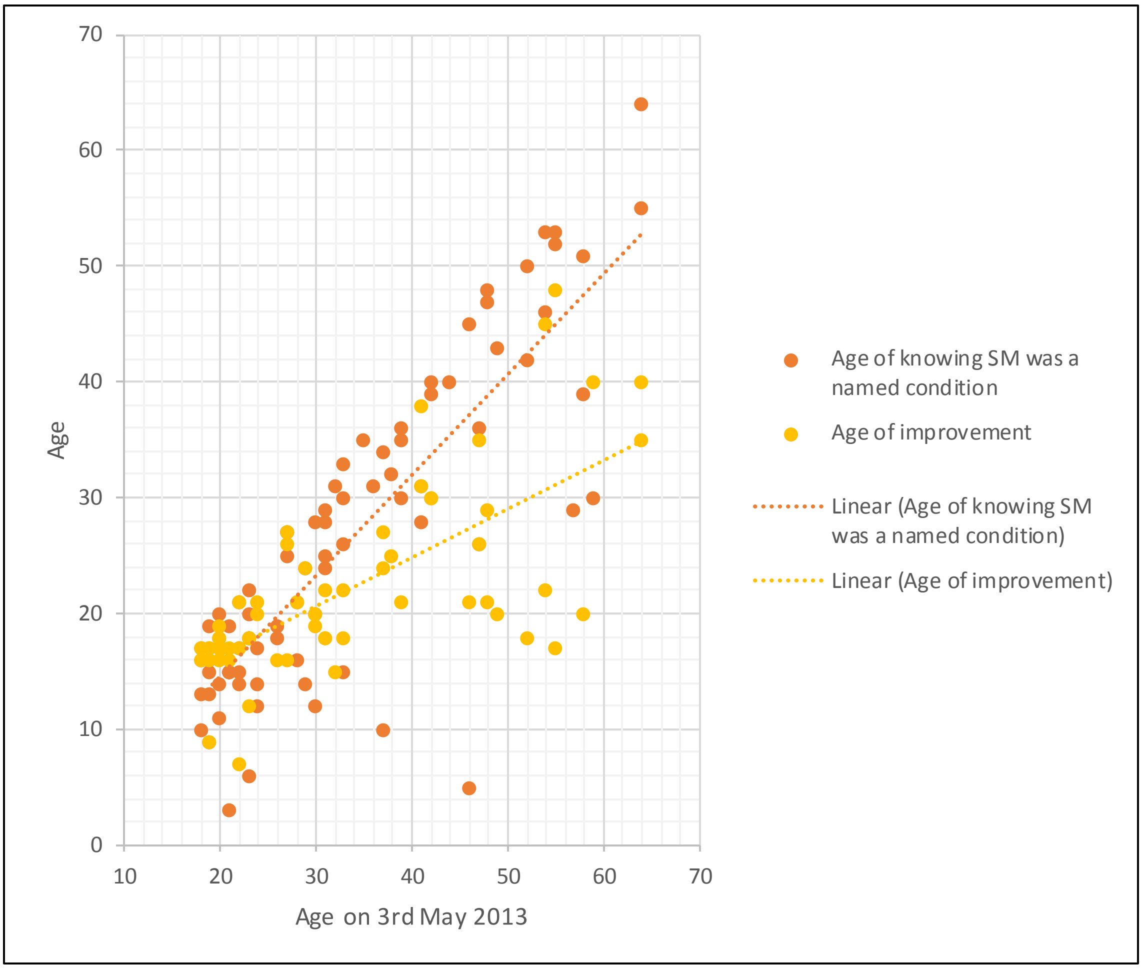

Figure 14 — Combined scatterplot of age of improvement and age of knowing SM was a named condition vs. current age

Figure 14 indicates that many participants (particularly older ones) improved before they knew that SM was a named condition. It also indicates a linear relationship between age and age of improvement and age and age of knowing SM was a named condition.

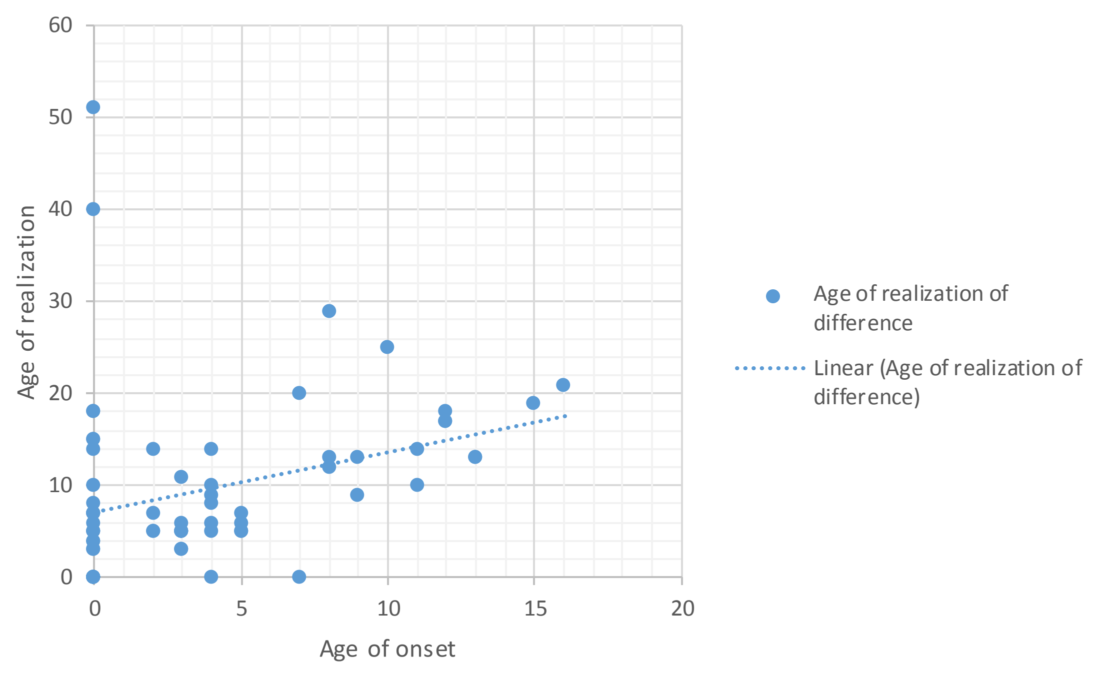

Figure 15 — Scatterplot of age of onset vs. age of realization of difference

Figure 15 indicates a linear relationship between age of onset of SM and age of realization.

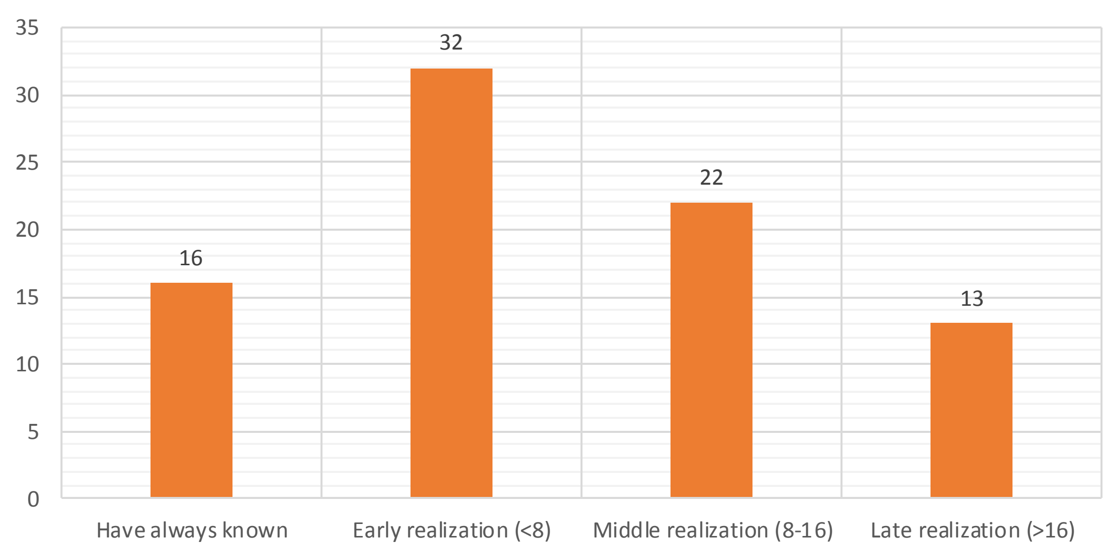

Figure 16 — Frequencies of ages of realization

There were 16 participants who suggested they had SM from birth, detailed further in Figure 16. While most realize their difference prior to age 8, there are also late realizations -the latest, as indicated in Table 6 (and pictorially in Figure 15), being 51.

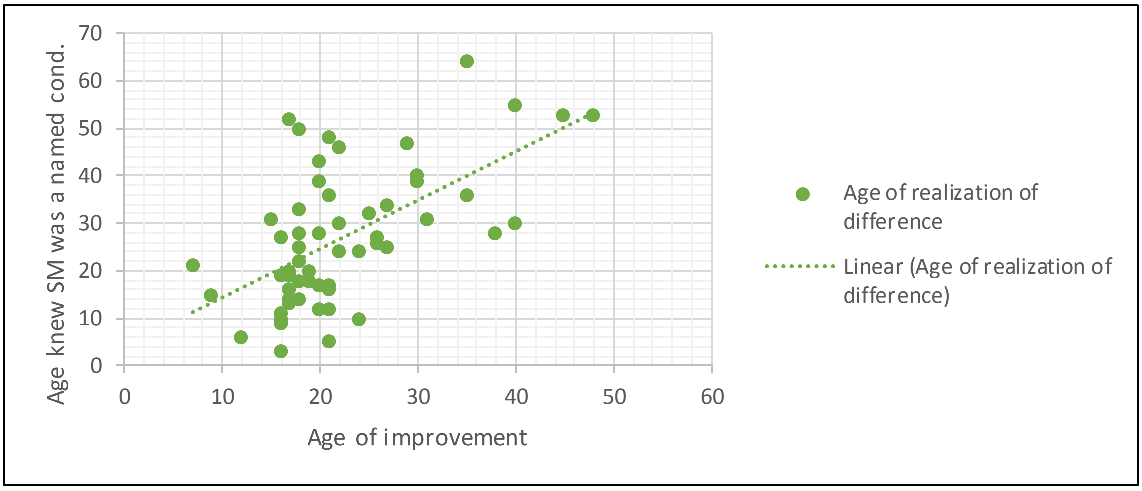

Figure 17 — Scatterplot of age of improvement vs. age knew SM was a named condition

Figure 17 demonstrates a potential linear correlation between age of improvement and the age at which a participant knew that SM was a named condition. While the correlation is significant, 50% of participants improved in a relatively narrow range between age 17 and 26, as shown in Table 41.

Table 41 — Percentiles for age of improvement

Percentiles (age of improvement)																		
5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95
11.8	16.0	16.0	17.0	17.0	17.7	18.0	18.0	19.6	20.0	21.0	21.0	22.0	24.0	26.0	27.4	30.2	35.3	40.3

Performing a means-split on age (age=33.43 – see Table 7), to investigate differences in "key ages" for older and younger participants, yields the statistics shown in Table 42.

Table 42 — Contrasting key ages after performing a means split on current age

	Younger than average (<33.43)		Older than average (>=33.43)		*t*-test
	N	**Mean (SD)**	**N**	**Mean (SD)**	
Age of onset	42	4.19 (4.35)	27	3.15 (4.66)	*t*(67)=-0.95, p=.35
Realization of difference	51	8.18 (7.13)	32	10.50 (11.73)	*t*(81)=1.12, p=.26
Age of improvement / partial recovery	35	18.03 (3.95)	23	28.83 (8.89)	*t*(27.779)=5.48, p<.001***
Age of recovery	1	17.00	3	27.00 (11.27)	*t*(2)=0.77, p=.52
Knew SM was named cond.	51	18.51 (6.49)	32	38.59 (12.39)	*t*(41.836)=8.47, p<.001***

†Levene's statistic significant

The *t*-tests demonstrate that older participants (who would have turned 18 in 1998 or before) were less likely to know SM was a named condition until significantly later in life.

Additionally, the *t*-tests in Table 42 demonstrate older participants more likely to have *improved* later in life, which may be an indicator that improvement is related to public awareness. Thus prior lack of public awareness of SM may have been a block to improvement.

It *may* be that increased awareness and diagnosis of SM - due to an increase of research into SM in children after the publication of DSM IV – is having a beneficial effect on outcomes for children and adults with SM. This would imply that either (a) diagnosis implies beneficial therapeutic intervention; and (b) awareness, not least in sufferers of SM themselves (and between sufferers of SM who may engage each other via the internet), beneficially affects outcome.

Regarding (a): contrasting the SM severities at every age group for those who received a diagnosis and those who did not using an independent-samples *t*-test showed no significant results, thus one may say that receiving a diagnosis (and receiving any ensuing therapeutic intervention) did not, in itself, have a significant effect regarding outcome on the group as a whole. In other words the therapeutic interventions on offer so far are likely to be ineffective (as participants have indicated) or diagnosis is not followed up with intervention or support.

Regarding (b): there is likely to be some truth in the idea that self-help, connectedness and mutual-help among sufferers of SM does have a beneficial effect. From experience, older participants who had no access to the internet in childhood (because it did not exist) will have very much felt like they were the only person on Earth who could not speak for psychological reasons, never encountering or hearing of another like themselves. Nowadays, visiting YouTube for instance, can provide an immediate awareness that SM is not something that “you alone” suffer with. While it does provide some benefit to know “you are not alone”, finding therapeutic support, armed with that knowledge, is another matter however. From experience, finding tailored support as an adult is an impossibility, because professional awareness, while it may exist to an extent, is not backed up by any form of professional training: SM is viewed to be rare in children, even though it isn't, and non-existent in adults.

One could suggest that, on balance, this statistic - improvement as a function of age – may be factitious and likely to be a result of sample bias. First of all, those who recovered were less likely to take part in the research (and there will be more of these the older the participants get) thus older participants were likely to be those with more a more inveterate and longstanding presentation of the condition, by definition: they may have improved later due to that fact alone.

An additional factor is that older participants were less likely to receive parental or familial support for SM or professional support either. It is likely therefore, that for those older participants with more inveterate SM (who could not deal with their SM on their own, which most adults with SM have to) there was never an opportunity to access relevant help for their condition.

Evaluated through thematic analysis, participants realized their differences in terms of speaking in four predominant ways - as shown in Table 43.

Table 43 — How adults with SM realized their difference

Theme	**N**	**Percent**
I couldn't speak	43	64.2%
I didn't speak	5	7.5%
Others said I didn't speak / told me I had SM	12	18.0%
I had a fear of speaking or of others hearing my voice	7	10.3%

(Total)	67	(100%)

Most participants realized their difference because they *could not speak*, rather than because they were *afraid of speaking*. Fear of speaking or of having one's voice heard is relatively low down the list. This indicates that SM is, on the whole, an instinctive or at least a subconscious response. There were no differences regarding gender or age group of the participants.

Table 44 — Asperger Syndrome vs. autistic traits

		Have a diagnosis of Asperger Syndrome		**Total**
		No	**Yes**	
SM is an "autistic trait"	**No**	75	1	76
	Yes	5	2	7
		80	3	83

Just three participants had diagnoses of Asperger Syndrome (2 females and 1 male). This is fewer than may be expected for a sample of adults with SM of this size. However, seven participants deemed their own SM to be an "autistic trait": $\chi^2(1,N=83)=13.67$, p=.02* (Fisher's exact test) as shown in Table 44.

As shown in Table 45, asked what participants believed SM to be 31.3% of respondents indicated that SM is an *inability* to speak - explicitly using the noun *inability* entirely unprompted to do so.

Table 45 — What participants with SM believe their SM to be / how they described it

Theme	Younger male (N=12)	Older male (N=7)	Younger fem. (N=41)	Older fem. (N=25)	N (Total)
Inability to speak	5	2	12	7	26
Due to anxiety / as a means to regulate anxiety	1	1	7	5	14
Due to FNE / social anxiety	2	1	2	5	10
Throat blockage / mouth locked	0	0	9†	3	12
Fear of speech	0	0	2	4	6
Slowed thoughts / mind-blankness	0	1	4	1	6
Feeling trapped / behind a glass wall	0	1	2	2	5
Speech as a window to the soul / conditions of worth	0	0	1	3	4
Freeze response	1	0	2	1	4
Feeling incongruous	1	2‡	1	0	4
Subconscious response / unknown reason	0	0	2	1	3
"Neurological" disconnection between thoughts and speech	0	0	2	1	3
Self-protection	0	0	1	2	3
Lack of development of social skills	0	1	0	0	1

Additionally, many describe physical discomfort in speaking including experiencing a perceived blockage in the throat, feeling that their mouth is locked or clamped shut etc. However this effect was significantly more likely to have been experienced by younger, female participants†: $\chi^2(1,N=70)=5.00$, p=.03*. No male expressed these kinds of experience. Older males were significantly more likely to say that "feeling incongruous" with others was part of the explanation for their SM‡: $\chi^2(1,N=70)=11.75$, p=.02* (Fisher's exact test.)

Asked how participants recovered or partially improved, the themes emerging from the data are given in Table 46.

Table 46 — How adults recovered from SM or partially improved

Category	**Subcategory**	**N**
Education (N=7)	Having a 1:1 tutor at university	1
	Being at university / going to college	2
	Online education	1
	Becoming a lecturer / teacher	3
Work (N=6)	Going to work / changing jobs	6
Pushing myself / challenging myself / helping others / learning more about myself (N=16)	Being in a position where I help others	1
	Forcing myself to push my personal limitations / challenging myself	2
	Small achievements / tiny steps	1
	Putting myself in a position where I had to speak	1
	Forcing myself to speak	3
	Pretending to be someone else	2
	Getting to know myself better	1
	Talking for myself rather than being spoken for	1
	Online discussions groups	3
	Joining a singing group	1
Changing thoughts / how feel about oneself / circumstances or environment (13)	Change of circumstances (school / location / country)	6
	Worrying less about things couldn't control	1
	Stopping caring about what others think	1
	Accepting myself	3
	Meditation	1

	Going to the gym	1
Through children (4)	Becoming pregnant	1
	Having children	2
	Getting married	1
Asperger Syndrome (2)	Getting a diagnosis of Asperger Syndrome (AS)	1
	Learning to be open about informing others about AS	1
Using prescribed medication (6)	Venlaxafine (an SSRNI)	1
	Sertraline (an SSRI)	1
	Paroxetine (an SSRI)	1
	SSRIs (not specified)	2
	Medication (not specified)	1
Self-medication (5)	Alcohol	4
	Smoking	1
Therapy and crisis (10)	Modern psychoanalysis	1
	Speech therapy	1
	CBT	2
	Seeing a psychologist	2
	12-step alcohol programme	1
	Residential rehabilitation after self-harm	1
	Having a breakdown (thus having to seek help)	2
No reason (3)	No reason / spontaneous remission	3

Figure 18 shows the responses given by participants regarding whether their parents tried to find professional help for them in childhood. Only 20% of the parents of the participants sought help for their children.

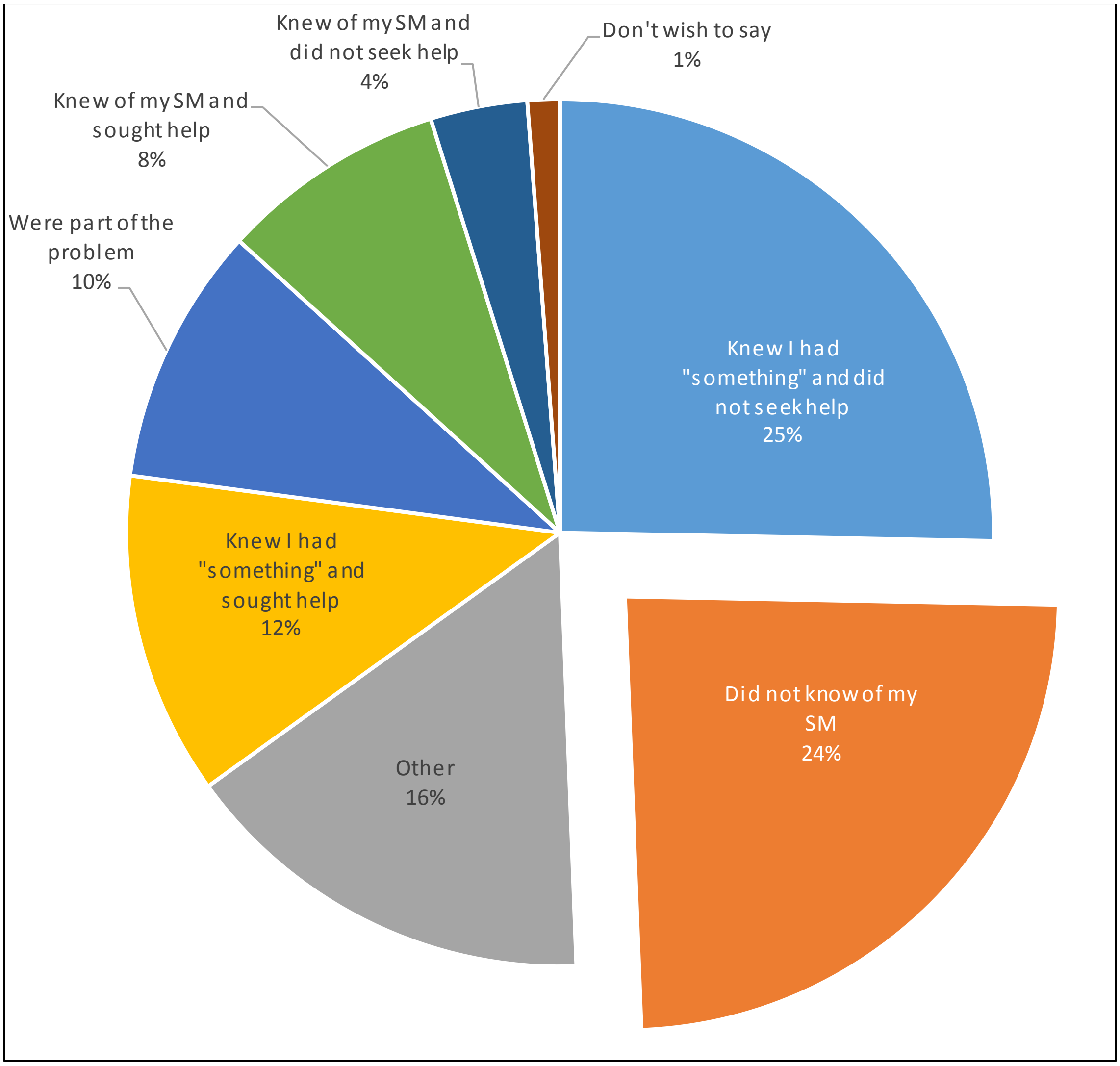

Figure 18 — Responses to “in childhood, my parents…” regarding seeking help

However, it has to be said that almost a quarter (24%) of parents were not aware of their child having SM. Plus, particularly in the past, there may have been a reluctance for parents to seek help for their children because of a fear that relevant authorities would “point a finger” at them.

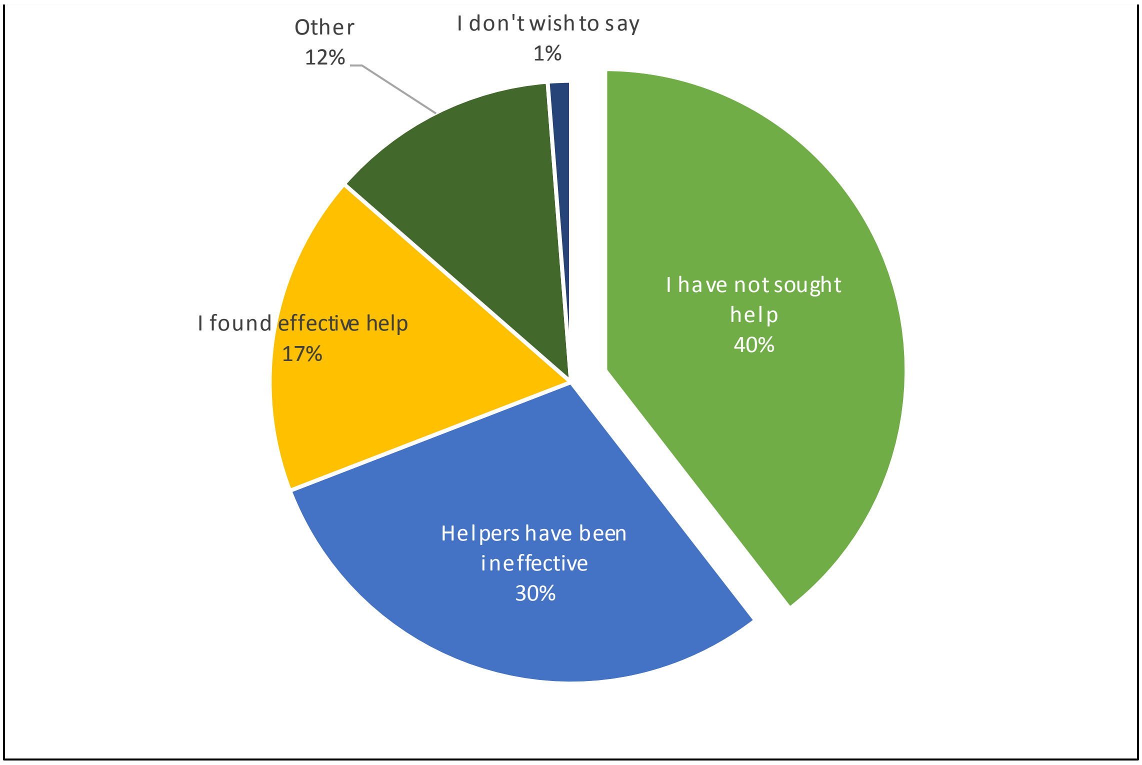

Figure 19 — Responses to "in adulthood…" regarding professional help

As shown in Figure 19, 40% of respondents have not sought help for SM in adulthood. Of those that did solicit help, most found their helper to be ineffective in working with SM.

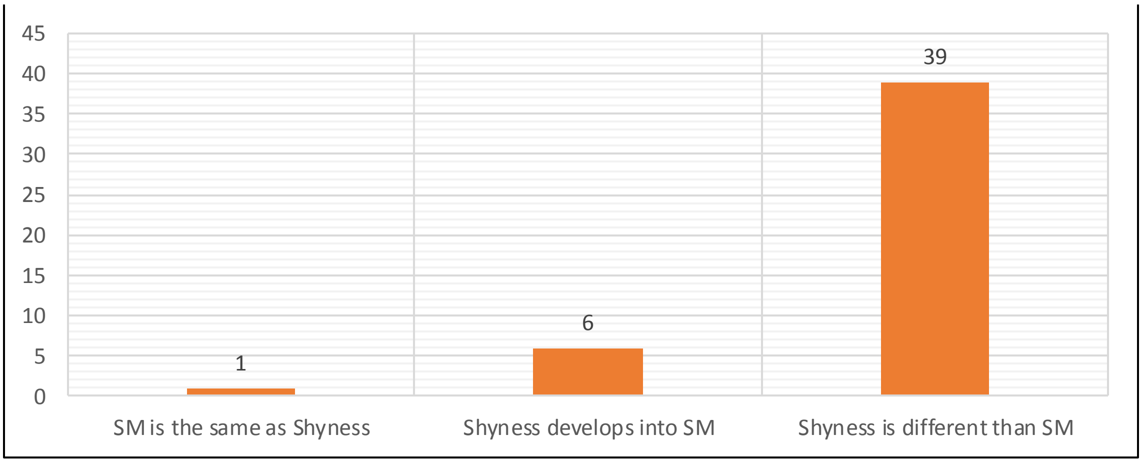

Figure 20 — Relationship between SM and Shyness

Participants were also asked about the relationship between SM and shyness in the second questionnaire. Of the 46 participants who answered this question, most said that SM is *different* than shyness.

However, Table 21 shows the mean self-reported severities of SM and Shyness at each age range, contrasted via a paired-samples *t*-tests.

Table 47 — Severities of SM and Shyness

	SM		**Shyness**		**Paired-samples *t*-tests**
	N	**Mean (SD)**	**N**	**Mean (SD)**	
Age < 5	62	4.11 (3.95)	35	6.37 (3.41)	*t*(30)=-3.06, p<.01**
Age 5-8	81	6.02 (3.19)	47	7.11 (3.12)	*t*(45)=-2.26, p=.03*
Age 9-11	82	7.11 (2.49)	50	7.30 (2.62)	*t*(48)-1.24, p=.22
Age 12-15	82	8.12 (2.13)	51	7.61 (2.46)	*t*(49)=1.07, p=.29
Age 16-19	81	8.20 (1.91)	51	7.39 (2.31)	*t*(49)=2.22, p=.03*
Age 20-24	71	7.54 (2.04)	46	6.67 (2.44)	*t*(43)=2.75, p=<.01**
Age 25-29	51	6.81 (2.11)	36	6.72 (2.08)	*t*(33)=0.89, p=.38
Age 30-34	41	6.49 (2.54)	29	6.03 (2.65)	*t*(25)=0.97, p=.34
Age 35-39	30	5.56 (2.82)	23	5.61 (2.86)	*t*(20)=0.96, p=.35
Age 40-44	22	4.92 (2.36)	18	5.11 (2.97)	*t*(15)=0.33, p=.74
Age 45-49	16	5.06 (2.68)	16	5.25 (3.24)	*t*(12)=-0.72, p=.49
Age 50-54	10	4.08 (2.81)	11	4.73 (3.13)	*t*(8)=-0.19, p=.86
Age 55-59	6	3.29 (3.66)	8	3.50 (3.02)	*t*(5)=0.24, p=.82
Age 60+	2	1.25 (0.71)	2	2.50 (0.71)	-

It is interesting that shyness shows a similar decay curve to SM. As such, SM may be a precursor for SM according this data, which implies a genetic or temperamental basis for many cases of SM.

Appendix H. Resource CD (containing SPSS files, etc.)