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# Lost Voices and Unlived Lives: Exploring Adults' Experiences of Selective Mutism using Interpretative Phenomenological Analysis

AARON S. WALKER AND JANE TOBBELL

University of Huddersfield, Huddersfield, UK

*Selective mutism (SM) is a rare condition whereby individuals remain silent in situations where speech is expected while they speak comfortably in others. Few studies thus far have attempted to understand this phenomenon from a qualitative perspective and have primarily focused on child sufferers of SM. The present study aims to address these gaps within the literature by presenting the subjective experiences of adult sufferers and to enable these excluded voices to broaden our understandings of this difficulty. Four adults with SM were interviewed using synchronous online techniques, data were analysed using an interpretative phenomenological methodology to gain an in-depth understanding which allowed participants' voices to emerge. A detailed analysis is presented of four themes connecting the narratives of participant experiences. Excerpts from the diary of one of the authors who had previously suffered from SM are also included to facilitate authenticity and transparency within this research. The results capture how selective mutism was experienced for these participants as the imprisonment of a true identity behind silence and how they have attempted to negotiate their unwanted identities of being selectively mute. These findings are considered in the context of previous literature and their implications and possible avenues for future research are discussed.*

**Keywords:** selective mutism; elective mutism; silence; isolation; qualitative; synchronous online interviews; IPA; insider research

## Introduction

Selective mutism (SM) is an uncommon difficulty whereby individuals display a consistent failure to speak in many situations where speech would normally be expected. The body of psychological literature concerning SM has been largely concerned with attempts to delineate diagnostic categories which can adequately describe this phenomenon. This has resulted in the development of a number of disparate etiological theories and conflicting conceptualisations regarding the nature of SM. Is SM a symptom of social anxiety disorder (Black & Uhde 1995; Dummit et al. 1997)? An extreme variant of social anxiety resulting from poor emotional regulation (Cisler et al. 2010; Scott & Biedel 2011)? A learned maladaptive pattern of behaviour (Bergman et al. 2013)? A manifestation of oppositional behavioural disorder (Reed 1963; Wergeland 1979)? Literature exists to support each theory, evidenced by the results of psychometric tests, comparative studies among

Correspondence: Aaron S. Walker, School of Human and Health Sciences, University of Huddersfield, Queensgate, Huddersfield, HD1 3DH, UK. E-mail: [u1052162@hud.ac.uk](mailto:u1052162@hud.ac.uk)

sufferers of SM and sufferers of social anxiety, and through clinician, teacher and parent ratings, observations, and descriptions. What has largely been missing from the literature until recently has been the voices of sufferers themselves. The present study aims to address this by employing the design and methodology of Interpretative Phenomenological Analysis (IPA) developed by Smith et al. (1999). This study uses IPA to achieve an understanding of SM as it is experienced by adult sufferers, in all its complexity, and as holistically situated within the meaningfully experienced life-world of the individual.

### ***Selective Mutism: Aetiology, Epidemiology and Conceptualisation***

Selective mutism was originally identified as a childhood disorder by Adolf Kussmaul (1877) and named Aphasia Voluntaria and later changed to elective mutism in 1934 (Tramer 1934). These terms reflect the assumption that children were consciously deciding to remain silent with their behaviours evidencing an oppositional behavioural disorder (Reed 1963; Wergeland 1979). SM has since been linked with anxiety related disorders and was reclassified as selective mutism in the *Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV)* (American Psychiatric Association 1994). This emphasised the possibility, as some have suggested, that SM is not a voluntary behaviour (Black & Uhde 1995). Despite this change, several recently published papers and the ICD-10 (1992) continue to refer to the condition as elective mutism (Remschmidt 2001; McNichols & Sharkey 2008), which highlights the continued confusion and disagreement regarding the nature of the difficulty.

The difficulty is not considered to be related to speech disorders or a lack of linguistic knowledge (American Psychiatric Association 2013). The prevalence of SM in the general population has been estimated to range between six and eight cases per 1,000 (Kolvin & Fundudis 1981; Cline & Baldwin 2004). Such studies have typically relied on clinically diagnosed cases and the condition as manifest in young children and thus there exists the possibility that these figures may be underestimates.

The age of onset for SM varies with the majority of cases reported involving diagnosis in the child's early years, often before the age of 3 or when the child first enters school (Standart & Couter 2003; Sharp et al. 2007). Mention of adolescent or adult sufferers within the literature is uncommon, and little is known regarding the long-term course of the difficulty. The overwhelming focus within the literature of SM as it is experienced during childhood may be a result of the tautological nature of diagnostic categorisation. Early research identified SM in children under 5 and this was reflected in the age of onset criteria in the *DSM-III* (American Psychiatric Association 1980), subsequent research employed the *DSM* criteria and thus the most studied population of individuals became children under 5 years of age. This cemented the notion that SM was a childhood disorder and has resulted in virtually no acknowledgement of adult sufferers within the literature. Further complicating factors have included the high rate of comorbidity of SM with other disorders. Various studies have linked SM to autism spectrum disorders, Asperger's syndrome (Bankier et al. 1999; Wolff 1995), numerous anxiety disorders (Kristensen 2000), childhood trauma (Omdal 2007), schizoid personality disorders (Wolff 1995), Fragile X syndrome (Hagerman et al. 1999), and dissociative identity disorders (Jacobsen 1995), among others.

The factors which may trigger SM are not clearly understood. Exposure to traumatic events has been suggested (Standart & Le Couter 2003), though evidence has relied largely on correlational studies concerning the onset of the condition. Others have argued that no link to trauma exists. Black and Uhde (1995) studied family histories, questioning the parents and teachers of selectively mute children. They found that only 4 in 30 cases reported

any significant traumatic events, arguing that there exists no evidence of a causal relationship between trauma and onset. Complicating this issue further is that research suggesting a link between trauma and onset have relied largely on the observations and interpretations of family, teachers, and researchers (Krysanski 2003; Standart & Le Couter 2003), neglecting any inquiry into the child's own experiences or understandings. This perhaps reflects clinical research paradigms in combination with the obvious difficulties in researching with children and further with children suffering from SM.

As well as traumatic events and behavioural factors, the family environment has also been implicated in the development of SM. Remschmidt et al. (2001) described the families of selectively mute children as conflictual and socially isolated. Using standardised biographic inventories with recovered adults the research found that 47% of individuals with SM had parents with marital issues. This was considered to be a relevant factor, despite research suggesting that marital problems may occur in comparable numbers in the general population (Copen et al. 2012). Neither does this explain the remaining 53% of participants where no significant problems were reported. Vecchio and Kearny (2005) conducted a study of children with SM and other anxiety disorders and found that in both groups the children's parents were significantly less socially active than in a control. However, it is unclear if this social inactivity is a result of the anxiety issues presented by the children or causal in the child's development of SM. Such research also demonstrates the lack of focus on the individual themselves, implicating the environment to such a degree that the perspectives and opinions of those with SM remain unconsidered.

Black and Uhde (1992) first suggested there may be a relationship between anxiety and SM after reviewing a case study of a 12-year-old girl with SM and suggested that this may be a universal characteristic of the condition. A further study by Black and Uhde (1995) of 30 selectively mute children found that 97% had also received a diagnosis of social phobia or an avoidant disorder of childhood while no other psychological or behavioural difficulties were identified. Dummit et al. (1997), in a study of 50 children with SM, identified anxiety or avoidant disorders in the entire sample, relying on structured self and parental report questionnaires. Similarly, Kristensen (2000) found that 71.4% of the 54 SM children in their study met the diagnostic criteria for anxiety related disorders. A comparative study by Cunningham et al. (2006) between children with SM and children with anxiety disorders found no differences when comparing parent and teacher ratings of internal and external behaviours between the two groups. These findings suggest that both difficulties are presented similarly to observers. These results have influenced the diagnostic categorisation of SM, and as of the *DSM-V* the difficulty has been repositioned as an anxiety disorder (American Psychiatric Association 2013). Evidence has again relied on the interpretations of parents, teachers or researchers and where children themselves have been included their input is typically limited to reporting on standardized questionnaires (Sharp et al. 2007). Understandings of the condition are therefore a reflection of the research methods employed to investigate it.

The theoretical and correlational link between SM and anxiety has also influenced the treatments which have been developed to help sufferers of SM. As no significant treatment protocols have been developed for SM, it is not uncommon for therapy to take the form of modified cognitive behavioural therapy (CBT) for generalised anxiety disorders (Fisak et al. 2006; Reuther et al. 2011). Research regarding the treatment of SM has generally been criticised as being methodologically flawed (Viana et al. 2009; Scott & Biedel 2011). Documented treatment approaches, especially in instances where multiple strategies have been employed, often fail to adequately document the details of treatment, minimizing the usefulness of such data for the development of effective therapeutic approaches.

Longitudinal follow-up data is rarely gathered and though therapy is generally believed to have greater efficacy with younger sufferers (Remschmidt et al. 2001) little is known about the long term development of SM in adults. Large scale studies which may demonstrate the effects of therapy are also problematic owing to the difficulties surrounding the identification of sufferers and the rarity of the difficulty. Furthermore, such outcome studies have failed to capture an in-depth understanding of the lived experiences of sufferers.

One attempt to gain an in-depth insight into the experiences of children with SM was conducted by Omdal and Galoway (2007). This study attempted to explore the experiences of three children suffering from SM, aged 9, 11, and 13. In an effort to avoid direct questioning, which it was suggested may cause the children to refuse to communicate, the researchers employed Raven's controlled projection for children (RCPC). RCPC requires that children write short stories about fictional characters including references to how these characters think and feel. Analysis proceeds under the assumption that these fictional characters mirror the real children's experiences and attitudes. Given the absence of rich, qualitative data from the point of view of sufferers, it is impossible to support or refute this assumption but an unintended consequence of such methods may be to disempower and neglect the voices of sufferers. It is possible that this approach may perpetuate the notion that sufferers are either unwilling or unable to discuss their difficulties directly through written dialogue or other means.

A further study by Omdal (2007) employed a form of thematic analysis to explore the recollections of six adults aged 31–60 who had suffered from SM as children. Though none of the participants had ever been diagnosed with or treated for SM, Omdal argued that they retroactively met the *DSM-IV* criteria. A crucial element regarding the maintenance of SM was found to have been the expectations of others who had adapted to, and in doing so reinforced, the silence of the child. Omdal suggests that this may have led to the individuals forming an identity of being silent children. It remains unclear, however, if this evidenced a conscious effort on the part of the child to then remain silent, as Omdal argues, or whether the children wished to speak but felt unable to do so, as others have suggested (Manassis et al. 2003; Roe 2011). The effects of such reinforcement regarding the identities of adults with SM has not yet been explored.

### *The Need for a Phenomenological Understanding*

Methodologies which fail to take into account the perspectives of those with SM may be presenting a misleading or partial representation of SM by reporting only how it appears to outsiders. For example, Kumpulainen et al. (1998) found that teachers of selectively mute children reported them as being shy, withdrawn and serious. While this may tell us how the condition appears to outsiders, it may be incorrect to assume that this provides any insight into the child's own experiences. In a study by Roe (2011), it was found that when 10–18 year olds with SM were asked to report their perceptions of themselves, the children reported characteristics such as being sociable, talkative, and humorous more often than they mentioned introverted qualities.

Within the literature virtually no mention of adults with SM has been made. One explanation put forth by Krysanski (2003) is that adults with SM are better at avoiding situations in which they are affected by their difficulties and thus rarely seek treatment. Despite the paucity of research in this area there is a possibility that adults with SM may be able to provide a much more comprehensive insight into the difficulty, being better able to make sense of and express their own thoughts and feelings than young children. The manner in which SM affects their lives may also be vastly different from how it affects children,

as adults are subject to very different social expectations and responsibilities and are situated within ecological systems which differ from those of children (Bronfenbrenner 2004; Spencer 2008).

Existing research has presented mixed interpretations and understandings of the difficulty and has relied largely on observer interpretations, rather than experiential accounts. SM is also regularly presented as representing a homogeneous group, with unique individual differences rarely being explored, once more this reflects the paradigms which underpin much of the literature. In prior research, where participant voices have been considered the results have been extremely illuminating (Roe 2011). We believe that many of the areas of confusion which have arisen from the therapist/researcher centric orientation toward the study of SM may be clarified through a greater effort to understand the phenomena from the perspectives of those suffering from it. This may be achieved by progressing our understanding toward a co-constructed awareness of SM by incorporating the voices of sufferers themselves alongside theoretical conceptualisations serving to address this current imbalance.

The aims of the present study are to gain an in-depth insight into SM from those who experience the difficulty and in doing so to further enrich our understanding through an examination of the lived phenomenon in all its complexity. This research also aims to further assert the existence of SM in adults in contrast to the common misconception that SM is a difficulty experienced solely by children. Exploring the missing component regarding the experiences of adults who suffer from selective mutism presents a unique challenge for phenomenological inquiry due to the nature of the difficulty and the silence by which it is characterised.

### ***Research Questions***

The research questions were: What are the phenomenological characteristics of the experience of selective mutism for adult sufferers? How do those with SM make sense of their difficulties and how is SM felt, both physically and emotionally? Semi-structured interviews were employed to help answer these questions. As SM would likely result in the inability for participants to speak comfortably in a face-to-face interview, the interviews were designed for and conducted using online instant messaging software, allowing participants to type their responses.

### **Method**

This research follows an interpretivist epistemology, taking the stance that gaining certain types of knowledge depends on moving beyond the goals of classification, prediction and generalisation. By interpreting the realities of individuals, the research is receptive to and allows for an understanding of the meaningful world of the individual. To this end, an interpretative phenomenological methodology was employed to analyse the accounts of four adults with SM using data gathered through online interviews. Supplemental data are included regarding one author's own experiences of SM. The present study was conducted in accordance with the ethical guidelines of the British Psychological Society and approved by the division of psychology and counselling of the University of Huddersfield. Prior to taking part all participants were fully informed as to the purposes of this study.

### ***Participants***

Participants were self-selected and recruited using advertisements directed at online SM communities. Individuals who expressed interest in taking part were then contacted by email to ensure that they were eligible to take part in this research. A total of four participants were identified who had been diagnosed with SM and who continued to experience these difficulties through adulthood who were not currently receiving treatment or therapy. It should be noted that some individuals suffering from SM may not have felt comfortable communicating even when using nonspoken methods, such as the text based interviews used in the present study, and thus were not eligible to take part in this research.

Four participants took part in semi-structured interviews: Lily, age 23, had experienced SM since the age of 12. Lily had received some support for her difficulties during her time at secondary school. Since leaving school Lily had remained unemployed, living with her family and socialising with a small group of peers online. Ben, 30, whose SM began in early childhood, was diagnosed during his early teens with SM and had also received treatment for depression. Ben had been employed after leaving school but left after several months due to difficulties related to SM. Ben retained contact with a number of close family members and currently lives alone. Sam, 21, had suffered SM from approximately age 8. Sam had engaged in cognitive behavioural therapy from the ages of 16 to 18 and noted that while he had overcome some difficulties as a result of that experience, such as depression, his life was still affected by SM and communication was limited to Sam's parents and a small number of friends whom Sam had met before the onset of SM. Hannah, 26, was diagnosed at age 17. Hannah had been unemployed since leaving school and remained living with her parents. Since the onset of SM Hannah has only been able to communicate verbally with her parents and has experienced reoccurring bouts of depression. None of the participants were currently receiving treatment for SM, though Hannah, Lily, and Ben each expressed a desire to seek support for their difficulties at some point in the future. No participant could confidently pinpoint a single event which had caused their difficulties. Hannah believes her difficulties began gradually after moving to a new home and losing contact with her existing friends, after which she became increasingly withdrawn. Both Sam and Lily suggested that their difficulties had been influenced by bullying while at school, but were unsure if this had been a result of their difficulties or had led to their worsening. Ben recalled speaking as a child and being somewhat shy during his early years, he would occasionally communicate with family members by whispering but over time this behaviour also ceased.

All participants had received clinical diagnoses of SM during their teenage years, and each had continued to experience the effects of this difficulty throughout part of their adult life. To protect the identities of participants all names used are pseudonyms. Passages from a diary, written by one of the authors (Aaron) prior to commencing this research, concerning his own experiences of SM are also included throughout the analysis as supplemental auto-ethnographic data.

### ***Insider Research***

To facilitate the authenticity and transparency within this research, we have chosen to include passages relating to one of the authors' own experiences with SM, employing autoethnographic methods where appropriate. Analytic autoethnography, as described by Anderson (2006), refers to research in which the researcher is a full member of the population being studied and is visible in the research. This method has been included for

two reasons. One criticism of traditional insider research, including insider IPA, is that the researcher often remains invisible within the research. As Clifford & Marcus (1986) describe, researchers risk becoming a “hidden yet omniscient presence.” Second, it was felt that these experiences would be beneficial to the goals of this research if they were reported and taken together, in both similarities and divergences, with the accounts of the other participants within this study.

As DeCruz and Jones (2004) note, insider and outsider status is complicated and researchers can be both simultaneously. The simple duality of insider/outsider status may be insufficient in capturing the true complexity of the issue, and this has been recognised within the present study. It is also recognised that insider status may be a potential dilemma in regards to illusory notions of automatic understanding or expected similarity and these issues are acknowledged. By incorporating the subjective experiences of one of the authors, positioned as both researcher and participant, there arises the possibility that such subjective experience may inform biases bringing into question the validity of this research. A number of methods were utilised to minimize the potential for any of the interpretations made to misrepresent the voices of the participants and maintain the validity of this research.

The incorporation of bracketing (Smith et al. 2009) allowed us to acknowledge our own understandings, attitudes, and preconceptions and, as much as possible, to set these aside throughout the analysis. An initial diary was developed detailing one of the authors' own experiences of living with SM. Throughout the analysis this diary was used reflexively to ensure that the analysis could proceed with a suspension of prior assumption or bias, as far as is possible, while allowing connections to emerge naturally between the participants' data and that of the author. Second, by combining the independent analyses of both authors, the risk of any potential preconceptions influencing the findings or their interpretation was further reduced. Finally with the inclusion of data pertaining to one of the authors' own experiences of SM, it is hoped that this additional level of transparency will demonstrate both the similarities and diversities in the lived experiences of SM. The inclusion of this supplemental data ensures that one of the goals of this research, to give a voice to those with SM, is fulfilled without compromising the researcher's own voice or the voices of participants.

### ***Procedure and Interviews***

Data were collected through the use of semi-structured interviews conducted online using instant messaging software (i.e., Skype). Semi-structured interviews allowed participants to give richer accounts of their own experiences than with more structured methods, as well as allowing an opportunity to probe further into interesting and unexpected topics. A schedule of two interviews lasting approximately one hour each was decided with all participants. These interviews followed an initial line of questioning which aimed to capture the narrative timeline of participants' experiences of SM. In most cases this section of the interview lasted for much of the initial hour. During the second interview, influenced by the findings from the previous exchange, a series of further directed open lines of questioning were explored.

### ***Interview Guide***

The initial interview explored participant histories with questions covering the age of onset, family and social life, the experience of receiving a diagnosis, the effects of SM on school/work life, and other areas of life which participants felt had been affected by

SM. While these topics provided a general outline to the conversations an effort was made to allow participants to influence the direction of the interview allowing their voices to emerge through a more naturally impelled conversation.

Avenues of questioning during the second series of interviews explored specific topics in greater depth. These included areas concerning the intrapersonal sphere and what SM meant in regards to an individual's sense of selfhood and agency; for example, "what does it feel like to be unable to verbalise one's thoughts in a given situation?" Other questions explored the interpersonal realm and how participants experienced interactions with others, such as family, friends and colleagues in relation to SM. A third line of questioning explored the embodied nature of SM and how individuals gave meaning to their experiences and how SM was felt both physically and emotionally, for example, "what thoughts occur after being in a situation where you were unable to communicate?" A final line of questioning explored the temporal nature of experience and how participants' outlooks of imagined projections of recovery, or of a continuation of their suffering, influenced their lives. Again participants were given the opportunity to direct the course of the interview. Interview questions which were posed by the interviewers were made with reference to the initial series of interviews and framed in ways relevant to each participant's situation and life narrative.

### *Data Analysis*

The interpretative phenomenological analysis followed the procedures documented by Smith and Osborn (2008) and Smith et al. (2009). This stage began with the process of bracketing (the *epoch*); through this reflective reduction we hoped to achieve the openness required for in-depth phenomenological understandings to emerge from the data. This was an ongoing process throughout the research. For one of the researchers who contributed the autoethnographic component of this study this was facilitated by their own documentation of their prior experiences with SM and a desire to understand which aspects of their own experience were unique, and which, if any, were shared. We believe that this subjective pre-experience of SM contributed to the genuine curiosity which fuels phenomenological inquiry.

During the first phase of analysis, the transcripts were each read and reread a number of times. At this stage the objective was to dwell within the data and to empathetically understand the life-worlds of each participant. Some broad concepts were noted as emerging at this stage: the impact of isolation, the physical and experiential components of living with SM and the notion of two distinct ways of speaking about the self, of at once being mute and yet also being trapped behind mutism. In the second phase, preliminary themes were highlighted and key sentences of each transcript were noted such as those which appeared significant to participants or which captured and communicated some essence of the nature of SM. In the third phase, various interpretative methods of identification including abstraction, contextualization, in which themes were clustered around temporal or narrative events, and subsumption took place. At this stage some themes, such as those relating to the self, were divided into separate subthemes. Both phase two and three were reiterative and fluid processes. Occasionally themes would be re-examined and clustered with other themes, joined with them, or noted as being potentially super-ordinate themes. Finally, these emergent themes were placed within a hierarchy: One group were placed as subthemes within the overarching theme of the self, while the second theme and its two subthemes were clustered as they reflected a deeper level of analysis capturing the pervasive and existentially oriented experiences of participants which underlie and influence numerous aspects of their experiences living with SM.

## Analysis and Discussion

Presented are two superordinate themes with two subthemes explicated from interpretations of the experiences reported by participants. The following themes concern dissociation and the otherness of SM, conforming to a silent self, isolation and a wasted life. All themes were evident across multiple participant accounts.

### *Theme 1: Selective Mutism and the Self*

The first subtheme concerns the embodied experience of SM, how participants described SM and how these descriptions demonstrate a sense of dissociation between a recognised 'true' identity and the silent identity that individuals were able to outwardly express. The emotional effects of SM are also described and these provide an opportunity to understand how SM may relate to comorbid difficulties such as avoidance and social phobia for some individuals.

The second subtheme relates to selfhood and how participants negotiated their identities with regards to the expectations and behaviours of others, which would often lead to difficult but inescapable situations. Issues surrounding self-esteem are also explored. Each theme is then discussed in relation to the existing literature and how this additional data may further elucidate upon existing theory.

### *Dissociation and the Otherness of SM*

In each participant's explanation of how SM was experienced, a striking image of dissociation emerged between a recognised and accepted identity and the embodied feelings surrounding SM. Hannah, who has been unable to speak to anyone other than her parents for the past nine years, explained:

*Hannah:* It isn't me, I know who I am and I'm not shy or quiet, maybe that makes it harder. When I'm with my parents I can be myself but around everyone else it's like it [SM] takes over. I can get the words in my head but something won't let me say them and the harder I try the more of a failure I feel like when I can't.

Hannah experiences herself as victim of SM, with a dissociation between her sense of self and the embodied experience of SM. By referring to SM as "something" and "it," Hannah provides a description which further removes SM from her own sense of self, giving SM its own separate characteristics. Hannah's description of SM "taking over" is almost as if she were describing a spiritual possession. Hannah's response to her selectively mute behaviour, viewing it as a failure, further demonstrates that for Hannah this is a fight against SM rather than the incorporation of SM into her own identity. The distressing features of simultaneously wanting to speak but being unable to do so are similarly described by Lily:

*Lily:* It's as if something in my head stops working so it won't let me talk. Trying to talk is like a pressure building up and I start shaking until I feel like I'm going to cry and I just have to get out of there. Out of the situation. It's frustrating . . .

Interestingly, Lily's choice of words are almost identical to Hannah's; "it won't let me." By referring to it as something "inside her head," she situates the "it" of SM simultaneously

within herself while also separate from her sense of self. In Lily's experience, it is the distress of SM, of wanting to speak with no success, which results in her attempt to withdraw from difficult situations. It is a possibility that such distressing experiences act as catalysts for the development of social phobia and social anxiety and may play a role in sustaining these comorbid difficulties.

Ben and Sam also described SM as feeling separate from themselves, referring to it as either unconscious or uncontrollable:

*Sam:* I know I can talk because there are people I do speak to but anywhere else it's like there's this subconscious roadblock that stops me saying anything.

*Ben:* I've always felt like I could talk if I could escape from this selective mutism.

My own experience of SM may be considered less severe than it once was, however, even in recovery the dissociation between identities, one accepted and one detached, remains evident:

*Aaron:* It never feels like anything I can control, even when all thoughts and efforts are directed towards speaking. Strangely the feeling that speaking is out of my own control extends to some situations where I *do* speak, which are still uncomfortable. Generally these are situations where speaking is required, such as asking for a train ticket. It's as if I were observing myself talking or being silent, both feel significantly different from situations where I feel as if I'm myself and can speak freely.

No participant reported experiencing SM as an accepted part of themselves or reflective of their felt identities. Instead participants described SM as distressing, uncomfortable, and separate from their sense of self. Jacobsen (1995) suggested that in some cases SM may be a manifestation of dissociative identity disorder, extrapolating this from a case study of an individual who described "entities that forbade him to talk." While certainly no such comorbid difficulty is evident here, it is interesting to note that the language used does evoke the sense of multiple selves. Indeed, the "as-if" is a central feature of depersonalization (Medford et al. 2005), a difficulty which often involves a feeling of no longer being in control of one's speech (Radovic & Radovic 2002). The way in which SM is expressed, as Hannah states, "It isn't me," evidences a sense of detachment and bears a striking resemblance to the feelings of unreality described by Radovic and Radovic (2002) in their phenomenological analysis of the language of depersonalization. Specifically they reported how, when dissociative experiences are described, bodily aspects or processes may be felt as if they do not belong, just as the silence of SM may not seem to belong to the individual.

Feelings of frustration and disappointment described as stemming from the embodied experience of SM correlate with, and expand upon Roe's (2011) findings, in which children reported that SM often made them feel frustrated, abnormal, or inferior. From participants' experiences described here, by Hannah and Lily, it can be seen how those feelings can be a direct result of the desire to speak and the inability to do so. This contrasts with the interpretations of Omdal (2007), who suggested that the participants in his study were determined to maintain their mutism. The interviewees here instead conveyed their determination to speak, a determination and desire which results in a sense of frustration and failure when it could not be fulfilled. Omdal (2007) suggested that the determination to remain silent was partially caused by individuals with SM feeling that they would be unable to handle the

reactions of others if they were to suddenly begin speaking. While this may be an oversimplification of the issue, as it does not account for the issues identified here surrounding the embodied experience of SM, the reactions of others did appear to play an important role as an additional difficulty to overcome.

### *Conforming to a Silent Self*

The expectations of others were described as factors which reinforced the difficulties surrounding speaking while also contributing to the more concrete difficulties of social exclusion and isolation. Sam explained how the behaviours of others, even where employed to reduce his distress, contributed to what Sam refers to as the “impossibility” of speaking:

*Sam:* When I was at secondary school, because no one expected me to say anything it became kind of impossible to say anything, like, other kids just avoided me. Even the teachers would treat me differently. In History class the teacher would just skip past me when we had to read things out. On one hand it helped, I wouldn't have been able to talk anyway.

As Sam explains, there was a substantial dissonance between his desire to speak and to be treated the same as other children at school and the simultaneous belief that, regardless, his SM would thwart any wish to speak. Sam's statement that despite the behaviours of others he would not have been able to speak further illustrates the hopeless impossibility he has felt in such situations.

Ben, who had been briefly employed after he left school, provides an account of how his difficulties resulted in avoidant behaviours which further distanced others:

*Ben:* At work I'd just hurry from place to place or try to look busy so no one would talk to me, you know, small talk? That way I could avoid looking like an idiot, sometimes someone would catch me and I'd try to mutter something at them. I think they gave up after a while.

Ben provides a further insight into what motivates his behaviour beyond SM itself, in this case it is his desire not to appear foolish to others. SM has been hypothesised to be a manifestation of social anxiety disorder (Black & Uhde 1992/1995), with evidence from large scale studies suggesting that many individuals with SM also fulfil the diagnostic criteria for social anxiety (Ford et al. 1998). However, while there are similarities there also may be significant differences. It is possible that such comorbidity exists because of the low discriminatory power of the diagnostic criteria rather than extant psychological similarities. In Ben's description his goals are to avoid the humiliation that social interaction would entail. However, unlike social phobia, the fear may not be recognised as excessive or unreasonable; instead it may be considered to be an attempt at avoiding the distress of undesired mutism. The feeling of other's “giving up” on attempting to communicate mirrors Sam's earlier comment that no one expected him to speak, making future communication even more difficult, demonstrating the role that others and social groups may play in distancing individuals with SM. Hannah also described how SM may result in an inescapable loop:

*Hannah:* Besides my parents I don't have anyone to talk to. It's a circle I can't escape from. I don't speak so no one speaks to me and then I'm left alone and there isn't anyone to talk to . . .

Again a sense of hopelessness surrounds the situation, one from which escape seems impossible and no alternative is recognised. Each of these accounts conveys the message that these individuals have been relegated to silence because of a combination of their own behaviour and the expectations and behaviours of others; that if they could speak they would have no one to speak to, and that if they had someone to speak to they would not be able to speak.

These data contradict Omdal's (2007) suggestion that individuals with SM are determined not to speak because of a sense that others would "win" if they were to do so and the assumption that individuals with SM construct an identity based around being mute. The individuals in the present study consistently reported their personal identities as being separate, with this disparity between their personal and their socially negotiated identities causing them distress. The social environment and the behaviours of others are not described as reinforcing a sense of identity directly but rather reinforce the feeling that there are no opportunities in which to speak, cementing their status as silent individuals.

## Theme 2: Existential Concerns

The theme of isolation is complex and includes experiences of loneliness, interpersonal isolation and intrapersonal isolation, and the disconnect with one's own sense of self. For some this extends to a deeper existential isolation, described as if SM had caused an isolation so profound that it creates an unbridgeable gap between participants' isolated worlds and a "real world" inhabited by everyone else.

The second subtheme explored participants' experiences of regret and the feeling that SM has resulted in an unfulfilled and meaningless life, including descriptions of how participants felt it impossible to integrate into what they consider to be normal social roles alongside their difficulties with SM. How this results in a sense of regret, and the implications of that regret are also discussed.

### *Isolation*

Descriptions of the isolation caused by selective mutism pervaded participant experiences. For Ben the isolation was described as transcending interpersonal relationships, being felt as a separateness from the world of others. Ben, whose SM had affected him for almost 30 years, the longest of the participants in this study, describes the fusion between interpersonal isolation and a more pervasive, all-encompassing existential isolation:

*Ben:* It's like that scene from scrooge where he looks through the window and he can see people having fun being together. I'll always be stuck outside looking in.

*Interviewer:* What kinds of situations have made you feel you feel like that in the past?

*Ben:* It's all the time. When I'm alone but even when I'm not. When I'm with my family, special occasions, weddings and christmas types. Everyone will be having fun, talking about their lives and all the stuff they've done, it seems so far away that world. I just listen and I'm there, but I'm not really there, you know?

In Ben's description, the sense of interpersonal isolation is clearly evident. Ben had described much of his life as being devoid of social contact, beyond such family events as he describes here, yet even in these situations he feels separate, and his sense of isolation

remains. From this we see that Ben's isolation moves beyond the psychosocial loneliness which arises from an unfulfilled desire to be with others (Carr & Schellenbach 1993) to a much more fundamental sense of separateness. This sense of separation from the world is the core feature of existential isolation (Austin 1989; Bekhet et al. 2008). Though existential isolation is viewed as an inescapable part of life, a result of being aware of our own existence, most individuals deal with existential loneliness only as a result of distressing or life-altering events. According to Yalom (1980), most of us deal with such distress by turning to loved ones for reassurance, trading the lonely "I" for the comforting "we." Heidegger similarly described how we may stave off existential concerns surrounding isolation through "absorption in the world," returning to the everydayness of life (Heidegger 1927). These defences against isolation, however, may not exist for those with SM. As Ben states, "that world" of normality inhabited by everyone else is not a world which he feels he is part of. The comfort of "we" similarly seems nonexistent as he describes even social gatherings as isolating experiences. This relationship between SM and isolation also reflects Heidegger's concept of "thrownness" (Heidegger 1927). Thrownness refers to the state of finding oneself in an existence that was not chosen and which we are powerless to alter. This state is thus also characterised by feelings of helplessness; a subject which was encountered in Hannah's discussion surrounding her thoughts on a future with SM:

*Hannah:* I don't think things will get better, if anything they'll get worse. My parents won't be here forever, I don't know what I'd do. How can I function in the real world when I can't even speak.

The notion of a real world which one is not a part of is again apparent. Heidegger described such unfamiliarity with the world using the term "uncanny," the sense of which leads to an awareness of one's isolation. Here Hannah also conveys her sense of helplessness and a belief that things will not improve, focusing on the eventual death of her parents, who represent her link to the real world. There is substantial literature concerning the effects of loneliness and isolation, overwhelmingly it has been linked to depression (House et al. 1988; Cacioppo et al. 2011), a difficulty often co-morbid with SM (Yeganeh et al. 2006) and which three of the four participants interviewed had suffered from. Depersonalisation has also been linked to isolation (Rokach 1988) and from participants' accounts of their experience it can be seen how SM results in similar feelings, and how it separates individuals from the everyday world of normality.

For each participant in this study relief from isolation seemed unlikely to come from social situations which involve direct contact with other people. Participants described direct contact as distressing because it made their difficulties more apparent, resulting in feelings of abnormality, frustration, and disappointment. However other means of social interaction may lessen those difficulties and enable a sense of belonging:

*Lily:* Talking to friends online helps a lot, that's when I can feel normal. Though sometimes it has the opposite effect too, someone might say something and I realise how not normal my whole situation is. But online I can be myself and say what I want without any of the stress and anxiety, even if I'm not really there with someone.

Though it is clear that online interaction is not a perfect substitute, as Lily still feels abnormal on occasion, online communication does appear to partially fulfil the need for socialisation and restore a sense of normality. The important sense of normality that can be achieved through talking to others online is one I have also experienced:

*Aaron:* Having friends to speak to online was a huge help. It reassured me that despite having SM I could still communicate with people; I often worried that perhaps I'd forgotten *how* to talk to people. At first communication was limited to written text, but I eventually began speaking, and comfortably.

### *A Wasted Life*

Regret, the powerful and distressing sense that things would have been better if only they were otherwise, has two causes: It is a product of interpretation, a sense of dissatisfaction with the outcomes of one's life in comparison with imagined alternatives, and the transiency of existence and the impossibility of changing the past (Yalom 1980; Zeelenberg et al. 2000). Here SM is described as causing the events which result in regret; the hopelessness of SM also makes the sense of regret extend into imagined futures, just as unfulfilled as interpretations of the past. The "if only" of regret was a recurring topic in each interview and was often tied to expectations that individuals felt were placed upon them. Lily provided several examples of these expectations:

*Lily:* A lot of the time I worry about things I haven't done, that I should have.

*Interviewer:* What kinds of things?

*Lily:* All the things normal people do. I could have gone to university, I always did well at school. But it was different there, teachers knew about my problem. Maybe I'd have been able to get a job and be in a relationship. A lot of the time I imagine what my life would be like if I didn't have selective mutism.

Lily expressed how it was the "normal" everyday roles which she felt she was missing out on. It can also be seen how Lily's sense of abnormality is taken to the extreme; it is not some but *all* the "normal things" she feels she has not done. Lily also compares the roles of adults and children: where at school her sense of "abnormality" was recognised and accommodated, no such accommodation is expected in the environments of work or higher education. Although these are Lily's own expectations, they may also be seen as more general social expectations (Mossakowski 2011). Being part of further education, being employed, or in a relationship may be seen as social roles which young adults are expected to fulfil, roles which the reality of SM renders impossible from Lily's perspective.

For Ben, regret is described as an inescapable pit and his concerns surround his sense of missed opportunities to express himself to those he cares for:

*Ben:* It's a wasted life, maybe that's why it doesn't feel like life. I'm stuck in a hole and life is going on around me. Nothing changes for me. It can be hard with family, people who I care about and who care about me, but I don't get to be me or say the things I want to. One day they won't be here anymore.

Ben describes his predicament as if he is stuck in a hole. Being trapped in a hole or pit is a common metaphor for depression (Rhodes & Smith 2010). Ben's sense that life is going on without him suggests feelings of abandonment, isolation, and of going unnoticed. His regret centres on missed opportunities with his family and his final line evokes a powerful image of the temporality of life: one day Ben's abandonment and isolation may be a concrete reality. Heidegger described how regret, being related to the temporality of existence, is always inextricably linked to death, and the discomfort and fear which arise from them both may be summed up as a fear of "the impossibility of further possibility" (Heidegger 1927).

Though Ben's experience suggests little in the way of further possibility, as his SM prevents him from not only speaking but from being himself. Regret may also stem from ontological guilt, which describes feeling that one has failed to live up to one's own potentiality (May 1986) rather than social expectations. In Ben's case, this is demonstrated by his feeling that if only he could be himself then things would have been different. Because of how SM has been described, as if there is a core self capable of speech, possibly even a talkative and outgoing antithesis of SM, and the reality of a silence which feels uncontrollable, the sense of ontological guilt may be profoundly felt. The regret of silence may also merge into a shame of silence, an experience which Hannah describes:

*Hannah:* The longer it goes on the more things I miss out on. Sometimes I feel ashamed because of that, and relying on my parents too much because it's not normal. I'm 26 and can't do any of the things I should be doing. Even things like going to a store are too much. I have no money of my own, how am I supposed to get a job when I can't talk to people. I don't like to think about the future, or the past. I can never go back and do those things, thinking about life before I had selective mutism is hard too, it just reminds me how bad my life is now.

The onset of SM for Hannah, around the age of 17, is considerably later than most reported cases (Krysanski 2003). Hannah's experience may be unusual in this regard as she is able to recall her experiences prior to the onset of SM, which were not limited to childhood. Such recollections are evidently painful and perhaps more starkly illustrate Hannah's sense of shame concerning missing out on life and the shame she feels concerning her reliance on her parents.

Shame is intrinsically related to the social world; we feel shame because we project ourselves into the minds of others and imagine what they must think of us. The result of shame is often the attempt to hide the source from the scrutiny of others. In Hannah's case her sense of shame surrounds many factors of her life, her silence, her lack of income and employment, and her dependence on her parents. Because shame may be avoided by attempting to hide it from view, shame is closely connected to the threat of rejection (Kaufman 1996). A phenomenological analysis by Karlsson and Sjoberg (2009) concerning the experience of shame found that such experiences often incorporated a deep sense of exclusion and loneliness. Loneliness, as previously discussed was deeply felt by the individuals in this study and was experienced as a product of the debilitating silence of SM. Regret, and the shame which it entails, may be a less visible but substantially powerful force in maintaining one's isolation due to fears surrounding the exposure of shame. This may be an aspect of SM which is limited to or felt more profoundly by adults. Roe's (2011) study found that less than half the adolescents questioned reported feeling embarrassment at their situation. It is a possibility that such feelings worsen with age. As with Lily's experience of school being accepting of her SM, while higher education and work were viewed as being far less tolerant, Hannah's concerns also pertain to her changing role as an adult. Hannah's additional remark of "I'm 26" implicitly suggests that her reliance on her parents, and any related guilt, would be significantly less distressing were she younger.

I have experienced similar regret and the fear of an unfulfilled, lonely and very silent future. I have also experienced feeling as if life had moved on without me. However, in my experience, those feelings were able to become the initiators of change:

*Aaron:* The efforts I've made so far to overcome SM have, I think, primarily been a fight against what would otherwise be a very bleak future. It's hard to imagine what it

would be like to feel normal, to be in any situation and just speak without feeling anxious or uncomfortable, and without trying to fight off the feeling that at any moment selective mutism will kick in, and make me either stumble over my words or fail to say them at all. But I do have proof, life events, which I can look at now and say that despite SM I achieved some sort of normality, even if I didn't feel it at the time. Some are what would once have been unimaginable, such as giving a presentation, or delivering a lecture. Even small everyday things such as asking for a train ticket or ordering a meal are reminders that SM can be overcome.

## Conclusion

The data presented expand on prior research, which has largely focused upon the difficulties encountered during childhood, by identifying and exploring the worlds of adults affected by SM. Moreover, it demonstrates that SM sufferers' voices can be represented and that these voices shift our understanding of SM. From participant data it can be seen how these individuals have become isolated from society and how this may lead to a cycle which sustains SM. This research, albeit with a small participant group, has shown that the experiences of adults with SM may be characterised by a profound sense of loss, of one's identity, of one's past and future, and of one's social interactions. It is difficult to say if these experiences are representative, but at a minimum the research has highlighted gaps in the existing SM literature and problematises some existing understandings which have excluded the voices of those with SM. Although IPA and existentialism are closely linked, the emergence of such a profound existential awareness among participants and the themes which encapsulated their experiences were unexpected. Perhaps such an awareness of the issues of temporality, death and the need for meaning reflect what Yalom (1980) termed a "boundary experience." Such a keen awareness may be the product of the isolation and loneliness which shift sufferers of SM from being-in-the-world to being-toward-death. Such feelings have not received a great deal of acknowledgement within the literature surrounding SM, however they provide important insights into the experienced nature of this difficulty and its relationship with anxiety.

Importantly, this research has succeeded in giving those with SM an opportunity to speak about their concerns, their worries, and their experiences through online interview methods. These data argue that future research must be wary of the disparity between how SM presents to observers and the complex way in which individuals themselves experience both SM and their own identities. The themes identified by this research, while highlighting the difficulties those with SM face, demonstrate significant resilience in the face of isolation and despair. Practical methods which facilitate a sense of inclusion and belonging may help adults with SM to rediscover their voices. The means of achieving this may be highly situational and depend upon the life circumstances and opportunities available to individuals which may be utilised in helping individuals to find, develop, or regain a sense of inclusion and belonging in their lives. Finally, this study has demonstrated that there are ways to hear the voices of those with selective mutism, if we are willing to listen.

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### About the Authors

*Aaron S. Walker* is a MRes student at the University of Huddersfield. His research interests include existential psychotherapy, mental health, phenomenology and narrative methodologies.

*Jane Tobbell, PhD*, is a senior lecturer in psychology at the University of Huddersfield. Her research interests include educational transitions using a community of practice approach.