

Chapter #8

SOCIAL/EMOTIONAL DEVELOPMENT IN ADOLESCENTS PREVIOUSLY DIAGNOSED WITH SELECTIVE MUTISM: A NARRATIVE APPROACH TO UNDERSTANDING

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ABSTRACT

Selective Mutism is a childhood anxiety disorder characterized by a total absence of speech in social contexts, despite the child being capable of speech and speaking typically in the home. Research on this intriguing disorder remains limited and a notable gap is the absence of research into the retrospective accounts of experiencing this disorder as a child; the child's perspective, and the child's voice is largely absent from the literature. This research seeks to fill this gap in the literature by affording previously mute children an opportunity to voice their subjective experience of the disorder. A narrative approach was employed to explore the experience of selective mutism in 12 previously diagnosed adolescents, and its effects on social/emotional development and identity during the critical period of adolescence. The research also explored how the selectively mute child made sense of their symptom and the years of self-imposed silence. A qualitative approach using thematic analysis of the narratives revealed commonalities across individual experiences in terms of identity construction, fear of change/difference, isolation from peers, and a move from self-protection to coping. Narrative accounts afford a unique perspective on selective mutism, and how it might affect early development and self-identification.

Keywords: selective mutism, anxiety disorder, social anxiety, identity construction, social/emotional development.

1. INTRODUCTION

Selective Mutism is a childhood anxiety disorder that is characterized by a total absence of speech in social contexts, despite the child being capable of speech and speaking typically in the home, with his/her family. The most recent edition of the Diagnostic Statistical Manual (DSM-V) removed the disorder from a placement in Other Disorder of Infancy, Childhood, and Adolescence and classified selective mutism among the Anxiety Disorders, due to the large similarities with social anxiety and social phobia. Indeed, as selective mutism is etiologically similar to anxiety disorders, it is often comorbid with social anxiety disorder, as children with social anxiety disorder and selective mutism often experience comorbid symptomatology, including but not limited to anxiety (APA, 2013). In common with social anxiety disorder, children with selective mutism typically demonstrate marked fear of scrutiny, humiliation and negative judgment but in the case of selective mutism, the fear seems to be largely crystallized around the act of speaking. A family history of social anxiety is frequently cited in the background (Chavira, Shipon-Blum, Hitchcock, Cohan, & Stein, 2007) and researchers recognize a familial trend of shyness and some anxiety in the parents of the selectively mute child (Black & Uhde, 1997). Traditionally, selective mutism has also been explored as a symptom of the specific anxiety

disorders of social phobia, separation anxiety, and posttraumatic stress disorder (Anstendig 1998). Selective mutism is now considered a distinct psychological disorder which manifests in childhood and typically «disappears» in early adolescence. Currently, a diagnosis of selective mutism is established according to the following 5 criteria on the DSM-V (APA 2013): 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. The disturbance interferes with educational or occupational achievement or with social communication. The duration of the disturbance is at least one month (not limited to the first month of school as many children are reticent or timid initially) The failure to speak is not due to a lack of knowledge of the spoken language required in the social situation. The disturbance is not better accounted for by a communication disorder (e.g., stuttering) and does not occur along with autism spectrum disorder or related disorders.

2. BACKGROUND

To date, little research of quality exists on this unusual and debilitating childhood disorder, its course and its treatment, despite a renewed interest in the disorder since its reconversion to an anxiety disorder in 2013. Due to its relative rarity, most research involves case studies or small groups. A review of the more recent literature indicates that selective mutism is held to be a rare disorder that is reported in considerably less than 1% of the population; although recent research suggests that the prevalence is greater and is increasing. A school-based sample yielded a prevalence of .71% (Bergman, Piacentini, & McCracken, 2002, Elizur & Perednick, 2003). Research supports the fact that selective mutism will typically afflict more girls than boys with a gender ratio of 1.5: 1 to 2.1 (Black & Uhde, 1995; Kristensen, 2000, Viana, Biedel, & Rabian, 2009). The mean age of onset is 5, although this may be younger as children may go unremarked and undetected in the first or second year of school as many children take time to adapt to the socialization required at school. Researchers in selective mutism also note that co-morbidity is frequent (disorders such as communication disorder, encopresis, depression, oppositional-defiant behaviors have often been cited in cases) with this disorder (Kristensen 2002).

In reviewing findings on the developmental perspective of selective mutism, research suggests that selectively mute children are temperamentally inhibited from infancy (Chavira et al 2007) and the personality of the selectively mute child has been traditionally described as strong-willed and stubborn (Omdal, 2015). An interesting and consistent finding across research conducted in various countries is that selective mutism is more prevalent in bilingual and immigrant populations; this has been documented in France, Israel, Britain, Norway and the United States to name but a few (Moro, 2002, Toppelberg, Tabors, Coggins, Lum, & Burger, 2005, Elizur & Perednik, 2003, Omdal & Galloway 2007). Recently, research focus has been placed on treatment and behavioral management of the disorder, and less focus has been placed on conceptualizing and understanding the disorder. Because the etiology of selective mutism remains unclear, there is disagreement among researchers regarding the most effective treatment approaches but the literature does provide empirical support for individual behavioral intervention of selective mutism (Oerbeck, Johansen, Lundahl, & Kristensen, 2012). Indeed, early intervention is considered a necessity as, if selective mutism is left untreated, the academic, social, and emotional repercussions can be devastating for the individual in adult life Shipon-Blum (2007). In reviewing the literature, perhaps one of the most striking gaps in the current body of knowledge on selective mutism is the absence of research into the retrospective account of experiencing this disorder as a child, and as an extension, how the disorder affected the

child's self-perception as they reached the formative years of adolescence and young adulthood. In fact, Omdal (2015) notes that –with a few notable exceptions-the selectively mute child's own perspective and information from formerly selectively mute persons is largely absent from the literature. Omdal (2007) completed qualitative research on adult experience of childhood selective mutism through interviewing of six adults who had been selectively mute; the interviews focused on the childhood and adolescence period. Data analysis led to identification of five distinct themes that connected the subjects' experiences: origins in early experiences perceived as traumatic; maintenance of selective mutism as a clearly defined social role; characteristics of social anxiety, loneliness and determination; a conscious decision to change; mixed reports of psychosocial adjustment in adulthood (Omdal 2007). Walker and Tobell (2015) attempted to explore the after effects of selective mutism through the exploration of the adult experience of selective mutism using retrospective accounts and diary entries made by one of the subjects at the time of the mutism. Four adults previously diagnosed with selective mutism were interviewed using synchronous on-line interviewing techniques and the subsequent data were analyzed to allow the subject's individual voice to emerge; analysis of the themes elicited through interviews captured the experience of selective mutism as the imprisonment of a true identity behind silence. Further analysis explored the subjects' attempts to negotiate the unwanted identities and their move to adulthood (Walker & Tobell 2015). This current research seeks to attempt to fill this gap in the literature on psychosocial experiences in selective mutism by affording the previously mute child an opportunity to voice their unique, subjective experience of the disorder as they enter the crucial developmental stage of adolescence.

3. METHODS

The subjects of the research were children who had all been the subjects of previous research six years previously. All subjects were female, bilingual in English/French and had met all the criteria for diagnosis of Selective Mutism as defined by the DSM at the time of the original research (DSM-IV). Their ages had then ranged from 5 to 11 years and the symptom of mutism had been present from the outset and had lasted longer than 6 months before entering therapy. All children were entirely silent at school and in all social situations, but spoke freely in both languages at home. At that time, the main objective of the research was to examine the potential role of bilingualism in the etiology, prevalence, and expression of selective mutism (McCarthy, 2013). Other objectives included exploring the role of mother tongue in the construction of earliest identity and how a duality in language and identity construction could lead to vulnerability at critical periods in the child's development (such as entering school). The current research pursues the study of this select population and seeks to explore the subjective *experience* of mutism and its effects on social and emotional development at another critical period in a child's development- that of adolescence. As selectively mute children did not express their emotions about the disorder or its treatment during this period of their lives (Omdal & Galloway, 2007), the study also had as an objective to give voice to the symptomatology and how it was perceived by the child at the time-how they made sense of their own symptom and how they experienced the months or years of silence they had imposed upon themselves. The narrative approach was employed to allow for a more natural conversational type of interview in order to obtain detailed descriptions and reflections on their experiences in their own words, as well as to allow the interviewer the scope to pursue a promising line of inquiry.

The research employed a method of narrative interviewing (Chase 2003) which involved employing a number of semi-structured questions in the format to orient the interviewer, while the principle objective was to encourage the subject to reflect and explore their own experience as freely as possible. The subjects were female 12 adolescents (ages 12-16) previously diagnosed with selective mutism during the period of 2006-2010 when they had been part of an original study on bilingualism and selective mutism (McCarthy, 2013). All subjects had received therapy for selective mutism for differing periods of time within that period (ranging from a period of 5 months to a period of 2 years). The focus of the narrative interviewing was to give voice to the *experience* of selective mutism in terms of their subjective description of being mute in social situations, their social interactions, other people's reactions at that time in their childhood, their self-image, and their perception of their current adjustment as they navigated adolescence. All interviews were conducted by the researcher in one-to-one settings, with prior consent obtained from all subjects. Items were grouped under four headings:

- *How the selective mutism began*
- *How it affected relations with others at the time*
- *How it affected self-perception and identity at the time*
- *How they moved to coping*

4. THEMATIC ANALYSIS

The primary aims of the analysis of the data obtained from narrative interviews were to identify common themes across the individual narratives and to draw out the implications for understanding, conceptualizing and treating selective mutism. Further objectives included exploring the extent of social anxiety described by the subjects. As children with selective mutism have been shown to demonstrate substantially more social anxiety than a matched control group without selective mutism (Buzzella, Ehrenreich-May, & Pincus, 2011), the effects of the mute behavior on early socialization and early social identity were also targeted through the narrative interviews. The objective was the detailed analysis of the themes connecting the narratives of participant experiences in order to provide information on early social experiences for selectively mute children. To that end, a qualitative thematic analysis was used in analyzing the transcribed interviews and observational data. Thematic analysis had previously yielded useful information on the selective mutism experience in recent research conducted by Walker and Tobell on four retrospective adult accounts (2015), and this approach was deemed most pertinent in attempting to explore adolescent accounts. Analysis of the data taken from the 12 adolescent interviews elicited specific themes and allowed for the identification of four common themes that recurred with frequency in the 12 individual narratives:

IDENTITY AND IDENTITY CONSTRUCTION
FEAR OF CHANGE/DIFFERENCE
ISOLATION/ALIENATION
MOVE FROM SELF-PROTECTION TO COPING

4.1. Identity and identity construction

As the subjects were all approaching or in the period of adolescence, it is perhaps not surprising to find questions of identity central to the reflections of the subjects. Adolescence can be characterized by the need to construct a stable identity. All subjects interviewed recognized the strength of their early identity at school as being primarily for their silence. People are often fixed from outside themselves with labels that they must include or resist in their identity definition (Josselson & Harraway, 2012). This early label came to define the child's presence and their relationships to others in social contexts, and the children came to accept it. The fact that the children spoke freely, and often volubly, in their own home with their families may have contributed to the sense of a duality in identities- a public and a private identity. The narratives of the subjects frequently referred to the difficulty of moving from a recognized, early "identity" to an unknown identity. Omdal's (2007) research into the retrospective accounts of adults included twins who had not spoken outside the home all throughout their childhood; the adults were aware that the title of "the silent girls" had been conferred on them by the other children and they could not shed this title. This "mute identity" (Omdal 2015) may become a powerful screen for the child in social situations. In the case of the children in the current research, this "mute identity" may have allowed for a certain passivity but also a recognition and acceptance which was possibly comforting to the child. The following are some examples of the subjects' reflections on their identities and on the labels conferred on them at the time of their selective mutism.

« I was the silent girl in the class »

« I was the Shy One... »

« I don't know how it started but I was known as the girl who couldn't speak »

« I was considered « the baby » of the class and they had to speak for me »

« Even the kids in other classes knew who I was. Everyone called me « the mute » »

« I was just the girl who never spoke and that was that. »

« ...-they didn't think about it too much-just thought I was a mute. »

4.2. Fear of change/difference

The change in identity from the mute identity to a speaking –and therefore a more typical identity for a young child–was evoked in all of the narratives. Additionally, a strong desire for consistency, predictability and sameness was voiced in many of the narratives. This seemed more far-reaching than the early identity proffered by the mutism and spoke to the child's fears in general. Omdal (2014) noted that one of the children in a research study who seemed overtly willing to overcome her muteness and speak in social situations communicated a need for sameness through her writing as she observed that she did not want anything to be different, but wanted everything to stay as it was–she "wanted it like it was now" (Omdal, 2014, p. 120). Referring to the previous research on retrospective adult reflections, Omdal (2007) reported that the twins, known as the "silent twins" felt that they

could not start to speak, because if they did, then the other children would ‘win’. They found it difficult to be like everyone else, but demonstrated a retrospective awareness of this feeling of difference or otherness. The twins said that they feared changes, because they did not know how to cope with them. They did not feel comfortable about others expecting certain behaviors from them (Omdal 2007). This need for consistency and fear of change was evident in several of the narratives analyzed in the current research; 10 of the subjects interviewed reported strong desires for consistency and fear of change. The children wished to maintain their mutism and their mute identity within the classroom. Some reflections from the children’s narratives included:

« They got used to me being silent so I stayed that way. It was easier for everyone »

« It was just impossible to suddenly be like everyone else-I was used to being different »

« I was afraid of what would happen next -things were ok as they were »

« I guess I was scared...it was just- what would people think-how everyone would stare and judge- I’d never opened my mouth before »

« You can’t just go from the mute to a talker »

« I was terrified when I did talk I’d say the wrong thing »

« ...I think their view on me was that I was shy, speechless, and probably nice and I didn’t want to change that »

4.3. Isolation/alienation

Predictably, the narratives made frequent reference to feeling isolated from their peers. As the children were silent both in class and outside class (in the playground, at lunch, on class outings), they were often left to themselves. In this manner, they withdrew from the requirement to take part and thereby risk exposure. The inflicted –or desired-isolation became a part of their lives and may sometimes have felt safe. The symptom of mutism in a young child can provoke strong reactions in the people in their surroundings, and reactions may include avoidance. Omdal’s “silent twins” reported that during their childhood, they felt that everyone else was their enemy and it was “them against us” (Omdal 2007). These intense feelings and convictions of being alone and separate reinforced the need for silence for more than half of the 12 subjects interviewed. While there was little reference to feeling bullied or victimized in any way in the narratives of the current research, several narratives made reference to strong and recurring feelings of being outside the group. Such recounts included:

« ...mostly, they just ignored me and I hung out on my own-just walking around »

« When I think of it now I think it affected how I got along with the other kids-I was usually alone or to the side watching... »

« I took a book to school so I could read at lunch every day-they stopped trying to get me to talk and left me alone and I was fine with that »

“...I stayed alone and it was better that way”.

4.4. Move from self-protection to coping

Despite the obstacles, all of the children gradually began to speak in social situations. Typically, moving through a personal and gradual hierarchy of social situations and finding a means to cope with a build-up of social stress enabled them to move forward and cope more effectively in social situations. Overcoming barriers related to speech in more and more situations and towards more and more people, the child became motivated to give up the mute identity. In most cases, the decision to begin to speak was conscious and gradual; the children did not spontaneously begin to speak or suddenly feel comfortable within the group. Rather, change was effected slowly and cautiously. The motivation came from differing sources- new friends, a desire to play, a need to be part of the group-but the move to speech also came from a renewed sense of agency and efficacy. The child often began to see herself as someone not in need of such intense protection or preservation, but as an individual with a certain temperament that was acceptable and tolerable to the outside world. The fear of scrutiny, judgment and ridicule gradually became less intense as the child took the risk of speaking and being heard. This move to coping also affected how some of the subjects viewed their development in terms of personal maturity. Of note in several of the narratives, was the awareness that the feelings of fear and anxiety in social situations had not disappeared but had become manageable. Many of the subjects reported a need to make a concerted effort, to use their determination to push through social situations until the feelings had abated. Most subjects reported intense fear of being the center of attention and a reluctance to speak in public due to fear of being scrutinized and judged; the fear and anxiety related to the expectation, requirements and judgments involved in social interactions remained at a high level for all of the 12 subjects as they navigated their adolescent years. A high degree of self-control may be observed in their approach to change and in their continuing social interactions. Samples of narratives included:

« When I think of it now I think it affected how I got along with the other kids-I was usually alone or to the side watching and I got tired of it and wanted it to change so I knew I had to break through it »

« I still don't like new situations and meeting new people but now I remind myself not to think about me so much »

"I said to myself you have to push yourself now before it gets worse. I still have to push myself."

« I'm not sure how I started talking but I think it was gradual-it had to do with being so comfortable talking with someone that wasn't my parents or family ».

« I slowly started saying small things –like just a word- to my best friend and to my teacher and nothing changed drastically so I kept on going ».

« I'm still a little shy but I always do try to break through at the start because if not I will create a blockage for myself and it'll just get harder and harder »

« It got easier when I started talking and only thought about what I was saying and forgot the fact they could judge me »

5. CONCLUSION

The experience of selective mutism as a young child implies a variation in typical early social/emotional development as well as a different and unusual experience of school life and early socialization. In reviewing the narratives of the selectively mute, it would seem clear that this experience of selective mutism typically leaves a residual memory trace that is carried into the critical developmental period of adolescence and often later into adulthood (Omdal 2007). Identity construction is influenced and affected by the dramatic symptom of the mutism and the mute identity that it confers on the child; the mute « identity » itself in turn becomes a powerful obstacle to change and to development. Analysis of the individual narratives would suggest that the child may become trapped within this identity and may find it difficult to construct a more multiple and integrative self-construct or identity. The early, social « self » becomes defined by an absence, the absence of speech, and therefore of many typical forms of social bonding outside the home. A differentiation between a private self and a public self may develop; a private self that is open and free and verbal, and public or social self, which is governed by feelings of fear and shame and must be kept concealed. The selective mutism becomes a critical point of reference in self-identification and serves as a barrier for change. The child becomes imprisoned within this identity and their true identity is masked by the silence. Equally, the narratives reveal some commonalities of temperament and experience in that a desire for predictability and consistency is strongly expressed as well as a concomitant desire for lack of change. The narratives revealed a temperamental and behavioral inhibition frequently associated with anxiety, but the anxiety-provoking situation is the everyday possibility of judgment, ridicule or humiliation and the fear is of self-exposure. This leads to a developing sense of the self as requiring protection and preservation from the outer world-the world outside the security of the family-and, ultimately, a requirement to remain concealed and silent when exposed to the outer world. The need or necessity for silence in social situations may allow the situation to be endured, but the cost to the child in terms of isolation from peers and a sense of alienation from the world around them is great and the narratives indicate that this weighed heavily on the children as they went through this experience. The move to change is necessarily slow and gradual and requires sensitive guidance. Analysis of the narratives suggests the need to work slowly and gradually through different social situations is appreciated by the subjects and confidence in the self as a speaker and a communicator is gained little by little. In tandem, the acceptance of the self as a «shy» or inhibited individual in novel social settings is also gained gradually and a growing self-awareness is used as a means to support and encourage the self, rather than to inhibit and criticize the self. This, in turn, allowed for more openness and readiness in communication with others. The transition from a socially silent self to a socially communicative self was gradually negotiated.

Selective mutism remains a complex, intriguing and little understood disorder. The lack of quality research on this population may create misunderstandings and poor awareness of the disorder and its implications for children who experience it. Despite increasing numbers of children receiving this diagnosis, few studies to date have explored the personal understanding and subjective experience of the selectively mute and how the experience may affect later social/emotional development. By exploring the subjective narratives of those who have experienced the disorder first-hand, we may come closer to a deeper understanding of the many factors which may precipitate and maintain the disorder during the crucial years of early socialization, and how the withdrawal from social communication affects early social relations. While the population in this study is small, it

is larger than several of the previous studies in selective mutism and the qualitative analysis of the personal accounts of the subjects allows a unique perspective on what it feels like to be selectively mute, and how this experience might affect the child's development, self-concept, identity construction and self-identification in later years, especially as they encounter the challenges of adolescence. Equally, an understanding of the underlying themes may help to inform clinical practice and judgment in terms of treatment and management of selectively mute children. In spite of the inherent limitations of this research due to the size of the sample and the necessity for caution when interpreting retrospective accounts, these findings offer new insights into the experience of selective mutism, and on a broader level, the experience of pathology in childhood should be considered in the context of previous literature and implications and possible avenues for future research discussed. Future research should aim to further understand the underlying temperament, emotions, and contextual experiences that may give rise to the development and maintenance of selective mutism in young children.

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