SELECTIVE MUTISM

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Selective mutism (SM) is a disorder characterized by a consistent failure to speak in specific settings (e.g., school, social situations) despite speaking normally in others (e.g., at home). SM is a relatively rare but serious condition that causes significant social and academic impairment if left untreated. Since the publication in 2013 of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013), SM has been classified as an anxiety disorder and the name changed from *elective* mutism to *selective* mutism, reflecting a shift in the understanding of SM from an act of will to a lack of ability to speak in specific situations. This chapter reviews the clinical presentation, prevalence, course, etiology, diagnosis, assessment, and treatment of SM with emphasis on aspects relevant to practicing clinicians.

Table F.5.1 Shifts in the understanding of selective mutism over time

1877	1934	1994	2013
Neurologist Adolph Kussmaul: *Aphasia voluntaria*	Child psychiatrist Moritz Tramer: *Elective mutism*	DSM-IV: *Selective mutism* classified among disorders first diagnosed in infancy, childhood, or adolescence	DSM-5: *Selective mutism* classified as an anxiety disorder

CLINICAL PRESENTATION

"I can't start to talk, because then everybody will just talk about what I do…"

(Adolescent boy)

The cardinal symptom of SM is the failure to speak in certain situations, most notably in kindergarten or school. Thus, symptoms are typically context specific. This discrepancy in speaking behavior is central to the disorder but it often leads to misunderstandings and suspicion as both teachers and parents tend to think that children behave in all situations the way they observe themselves (e.g., if a child does not speak at school the teacher may think that she does not speak at home either). SM can also be person-specific (e.g., the child may be mute with some persons but not with others). Different individuals may increase or lessen symptoms considerably within the same situation. For example, friendly, funny people who talk and keep the "conversation" going independent of the child's active participation, are helpful. Children with SM often find it easier to talk to other children compared to adults. Some will occasionally be able to whisper to a best friend at school. The video clips illustrate the clinical features typically found in SM.

Click on the image to view a video clip of child with selective mutism

A feature of children with SM is that they differ widely in their ability to use nonverbal communication (e.g., eye contact, gestures, nodding and pointing). While some use nonverbal communication effectively, others are non-communicative and might not even laugh or cough in front of others. The latter are often unable to express their needs (going to the toilet, hunger, thirst, or pain), highlighting the potential seriousness of this condition.

In spite of the considerable stress experienced at school, school refusal is rare. SM is often comorbid with other anxiety disorders, especially social anxiety disorder, and with neurodevelopmental disorders, especially language disorders. Immigrant, bilingual children are overrepresented.

The clinical vignette of Ann illustrates the temperamental traits often found in children with SM. It also illustrates how inability to speak may be different in different settings, which may cause frustration due to people thinking that mutism is deliberate.

Typically SM has onset between 2 and 5 years of age but is usually not recognized until children start school, where speaking is an integral part of the learning and socialization processes. Children with SM are generally afraid to make mistakes and dislike being the focus of attention. Their "solution"—muteness and, sometimes, trying to be invisible—becomes part of the problem. When they occasionally *do* talk, they get everybody's attention, which they find anxiety-provoking, perpetuating mutism in a vicious circle.

Children with SM are often asked why speaking is so difficult; they generally find it hard to explain. Some older children with SM have described the feeling of having a great lump in the throat hindering speech. Children with SM exhibit significant social and academic impairment (Carbone et al, 2010; Remschmidt et al, 2001; Bergman et al, 2002). The video clips on the right side illustrate the typical symptoms in two children, a boy and a girl

"I'd really like to talk to you but something, and I don't know what it is, makes it impossible for me…"

(Adolescent girl)

Click on the images to view a documentary (Help Me to Speak) that follows two children with selective mutism. Part 1 (above, 12:15) and part 2 (below, 13:11) illustrate the symptoms and behavior.

Ann

Ann, a 5-year-old girl, was referred to the mental health services because of suspected SM. Her mutism had lasted since she started in kindergarten at age three. Both her parents and teachers had hoped that her muteness would improve spontaneously and thus postponed seeking help. Now, they worried that her lack of speech would continue at school and wanted help.

Ann had developed normally but parents described her as shy and "slow to warm up" in new situations and when meeting strangers. Both parents recognized this temperamental trait in themselves and her mother still struggled with social anxiety.

At home, Ann was a lively and happy girl. She spoke freely with both parents, her younger sister and a playmate. When the extended family was visiting, she talked to her grandparents on her mother's side but not to her father's parents, making them unhappy. They thought that her not speaking was deliberate and argued for putting more pressure on her to speak, resulting in conflict with the parents.

Outside the home, Ann spoke to her parents when no one was within earshot, but her parents had to speak for her in all situations, like in shops and at the dentist. When invited to a friend's party, she would go if a parent joined her but she did not talk.

In the kindergarten, Ann seemed happy but did not speak to either adults or children. She talked to her parents in the cloakroom but got silent when others appeared. However, she used gestures freely and communicated well with teachers and peers by nodding and pointing. She was always included in play and the other children often spoke for her and did not seem bothered by her lack of speech. This behavior stood in contrast with her first few months in kindergarten. At that time she cried extensively when the parents left and did not communicate with gestures. The increased nonverbal communication and general behavior in the kindergarten raised hope of a spontaneous remission of her mutism.

PREVALENCE AND COURSE

SM is estimated to affect approximately 1% of the child population; prevalence rates from 0.1% to 2.2%, depending on the sample and the diagnostic criteria used. Although similar gender ratios have been described, most research suggests that SM is more common in girls (girl/boy ratio of 1.5:1 to 2.6:1) (Bergman et al, 2002; Hua & Major, 2016). When one asks parents *when* symptoms started, they generally find it hard to pinpoint the onset and often say the child "has always been like this". This type of statement underlines a temperamental trait found in SM: behavioral inhibition—characterized by shyness, timidity, withdrawal, and fear of the unfamiliar (Gensthaler et al, 2016a; Muris et al, 2015).

The few long-term follow-up studies that exist show that although symptoms of SM can lessen over time, some persist. As adults these individuals typically suffer from communication problems and social anxiety and are at higher risk for other psychiatric disorders (Remschmidt et al, 2001; Steinhausen & Juzi, 1996). However, the pressure to speak diminishes because adults can more easily choose whom to be with and what they want to do.

ETIOLOGY

No single cause for SM has been found thus far. However, the understanding of this disorder has changed over the years from an act of willfulness of the child, to a lack of ability to speak in certain situations (see Table F.5.1). As for most child psychiatric disorders, it should be hypothesized an interplay of genetic, temperamental, neurodevelopmental and environmental factors, summarized below (for an overview of SM and a thorough examination of its etiology, see Cohan et al, 2006b; Muris & Ollendick, 2015; Hua & Major, 2016):

- *Genetic factors*. SM, social reticence and social anxiety run in families (Black & Uhde, 1995). A specific gene variation has been found to be associated with both SM and social anxiety disorder (Stein et al, 2011)
- *Temperament*. The behavioral inhibition trait (fearfulness and avoidance in unfamiliar situations) is generally associated with a greater risk for later anxiety disorders (Hirshfeld-Becker et al, 2007). Consistent with the link between social anxiety disorder and SM, there is also an association between SM and behavioral inhibition (Gensthaler et al, 2016a)
- *Neurodevelopmental factors*. Children with SM have higher rates of several neurodevelopmental conditions. The most prevalent are speech and language problems but elimination disorders and motor delay are also common. There is a small overlap with autism spectrum disorders and with lower intellectual capacity, although the majority of children with SM have IQ within the normal range (Kristensen, 2000; Cohan et al, 2006b)
- *Environmental factors*. Bilingual children are overrepresented in SM. Transitions such as starting school and meeting new people may trigger and are especially hard for children with SM. In contrast to shy children who will warm up over time, children with SM continue to be mute and withdrawn

DIAGNOSIS

Diagnostic criteria

- Selective mutism is characterized in DSM-5 by a consistent failure to speak in specific settings (e.g., school, social situations) despite talking normally in other settings (e.g., at home) (American Psychiatric Association, 2013)
- DSM-5 specifies that the selective absence of speech should be present for at least one month to establish the diagnosis. *This does not apply to the first month of school* as many young children are silent when they face a new situation, such as starting school
- Importantly, the failure to speak cannot be attributed to a lack of knowledge of, or discomfort with the spoken language required in the social situation
- The disturbance is not better explained by a communication disorder (e.g., childhood-onset fluency disorder or stuttering) and does not occur exclusively during the course of autism spectrum disorder, schizophrenia, or another psychotic disorder
- Finally, the child's lack of speech should interfere with daily functioning: The absence of speech hinders the child's capacity to function at school or in social interactions.

SM is called *elective* mutism in ICD-10 and is included in the section "behavioral and emotional disorders with onset usually occurring in childhood" (World Health Organization, 1990). The ICD-10 exclusion criteria include pervasive developmental disorders, schizophrenia, specific developmental disorders of speech and language, and transient mutism as part of separation anxiety in young children. The beta draft of ICD-11 available in August 2016 proposes to change the name to *selective* mutism, is included in the section on "anxiety and fear-related disorders", and has a description similar to that in DSM-5.

THE KEY DIAGNOSTIC QUESTION

Does the child speak normally in at least one setting (e.g., home) but show mutism in other settings (e.g., kindergarten or school)?

- If yes, ask parents to elaborate on the clinical presentation of their child's speaking behavior, how long the muteness has lasted, and what has been done, with what effect, to help the child.

In addition:

- Ensure that the child does not have a hearing problem.
- Gather information on the child's general developmental history (oral motor, motor, language) to exclude acute muteness due to psychological trauma or acquired brain damage.
- Information on academic functioning in kindergarten/school is mandatory.
- Assessment of nonverbal language and reasoning ability (intelligence) is advisable.

Diagnostic challenges

The diagnostic overlap between SM and several other child psychiatric disorders often found in the clinic can make the diagnosis of SM difficult. Neither DSM, nor ICD specify whether the criterion "consistent lack of speech" means speaking to adults. Of note, some children with SM speak or whisper to a "best friend" in school. Another challenge is whether *some* speaking in class (like in small groups of students, alone with a teacher, or with teachers and children in small groups) still qualifies for a diagnosis. In these cases, support for and against the diagnosis can be found in the degree of impairment the muteness creates. However, more specific guidelines do not exist. Clinical judgement of impairment must be used, and the decision is thus dependent upon the clinician's skills and experience.

Diagnosing SM in bilingual children is particularly difficult. They are often overlooked—their muteness being attributed to a lack of understanding of the new language. Often overlooked in this subgroup are comorbid speech and language disorders, masked by the muteness and bilingualism. Getting information on, or assessing language ability in the child's native language is essential. For diagnosis, the main point is that mutism must be prolonged or is disproportionate to the degree of second language knowledge and exposure (Toppelberg et al, 2005).

Diagnosing selective mutism in bilingual children

- Mutism should have lasted for at least six months
- Mutism is present in both languages
- There are associated symptoms of anxiety or inhibited behavior.

Comorbidity

Children with SM often present with symptoms of other anxiety disorders, particularly social anxiety disorder. Studies have found this comorbidity in about 90 % of cases (Gensthaler et al, 2016b; Oerbeck et al, 2014).

Separation anxiety disorder is common, especially in younger children. However, school refusal is rare. Neurodevelopmental conditions are frequent. The most prevalent are speech and language problems, elimination disorders, and motor delay. SM has been found comorbid with autism spectrum disorders in <10% of cases. Attention deficit/hyperactivity disorder is rare (Kristensen, 2000).

There has been some controversy concerning the understanding of oppositional behavior observed in some children with SM. Children with SM have been described over the years as controlling, stubborn and oppositional, often implying a primary problem in the family dynamics. The shift in DSM-5, where SM is understood as an anxiety disorder rather than a manifestation of oppositional behavior, is thus significant.

The largest study to date on children with SM (n=130) found that social anxiety was the most prominent additional feature. Almost half also had borderline clinical scores for speech and language problems—an important reminder as these problems may easily go unnoticed in these children. Another 45% showed borderline clinical scores on oppositional behavior. Only 12% had a "pure" social anxiety (Cohan et al, 2008). The authors suggest that the oppositionality shown by children with SM is often present only in situations that require verbal communication. That is, they become oppositional and non-compliant when pressured to speak when they are anxious about doing so.

Differential diagnosis

The symptom overlap often found in the clinic can make diagnosis difficult, particularly when using ICD-10 criteria, which requires excluding the presence of pervasive developmental disorders, schizophrenia, specific developmental disorders of speech and language, and transient mutism as part of separation anxiety in young children. According to DSM-5, SM should not be diagnosed if symptoms are *better explained by other disorders* such as a communication disorder, autism, schizophrenia or other psychotic disorder.

Although somewhat difficult, the importance of diagnosing comorbid neurodevelopmental disorders is underlined. One purpose of such diagnoses is to highlight areas of strength and difficulty so that appropriate support and intervention are organized in kindergarten or school. If the child shows multiple social and communication delays or mutism in the context of other socially odd behaviors, autism spectrum disorder is more likely the primary diagnosis. The large overlap between SM and social anxiety disorder is recognized in both DSM and ICD. For individuals with social anxiety disorder and suspected selective mutism, making an accurate diagnosis is essential. Gathering information from multiple sources on the presence of selective muteness is needed. Dismissing children with SM as just being socially anxious is potentially harmful.

ASSESSMENT

The diagnostic assessment of SM must be based on information from both parents and teachers to ensure accurate information on the child's failure to speak appropriately in certain social situations. A multi-informant perspective is critical due to the situational nature of the condition. Parents may in fact be unaware for a long time of the child's mutism at school. Evaluation generally includes a combination of diagnostic interviews and questionnaires completed by parents and teachers and behavioral observations of the young child. Older children can be asked to nod to questions or complete written questionnaires. Some young children with SM (aged 4 to 5 years) are able to complete "talking maps" with the help of a parent. However, the degree to which children with SM can convey information in this new, stressful situation, with unfamiliar adults is quite variable and not essential for a diagnosis to be made.

Diagnostic interviews

The *Schedule for Affective Disorders and Schizophrenia for School-Aged Children: Present and Lifetime Version* (K-SADS-PL) (Kaufman et al, 2013) and the *Anxiety Disorder Interview for DSM-IV Child and Parent Version* (ADIS-IV-C/P) (Albano & Silverman, 1996) are common interviews used. These interviews are designed for children 6-18 years, but adequate diagnoses can be made in children below age six as long as the behavioral concepts and the understanding of life interference is adapted to be relevant to a preschool child (Birmaher et al, 2009). Alternatively, the *Preschool Age Psychiatric Evaluation* (PAPA) (Egger & Angold, 2004) can be used.

PRACTICAL ISSUES IN ASSESSMENT AND TREATMENT

- Most children with SM cooperate in a structured test situation if they are willing and well prepared
- Parents can join in and assist in the presentation of items if the child wishes
- Before the testing starts, tell children that they do not have to talk to you
- Show the test material and explain alternative answering formats they can use, such as pointing, nodding, or writing responses (older children)
- The child is to sit beside the clinician, not opposite, as is usual during testing, to avoid direct eye contact that often makes these children uncomfortable. In this way both the child and the clinician focus on the test material in front of them
- Untimed tests of receptive vocabulary are preferable as children with SM can be slow to answer due to fear of making mistakes
- One useful test is the *Peabody Picture Vocabulary Test* (Dunn & Dunn, 2007) where the clinician speaks a word and the child points to the corresponding picture among alternatives. Other non-verbal tests intended to provide a quick estimate of verbal ability, scholastic aptitude, and intelligence can also be used
- For evaluation of potential articulation problems and the child's pragmatic language, parents are encouraged to use a digital recorder to record speech in everyday situations at home (e.g., playing, talking to a sibling or parent)
- Create joint attention using a pleasurable play activity rather than focusing on the child
- "Think aloud" when speaking (e.g., "I wonder if this will fit here?") rather than questioning the child directly
- Choose conversation topics connected to a pleasurable activity you do together or to other neutral topics, rather than the child's feelings or his/her personal issues
- Periods of silence are inevitable when working with these children. Some people find this silence awkward and tend to chatter it away. Work on being relaxed and be sure to give the child enough time to respond rather than chatter or talk for the child all the time
- After some time, calmly continue the "dialogue" even though the child may not respond verbally, thereby taking pressure off the child to talk, increasing its comfort and moving "the dialogue" forward
- Receive an eventual verbal response in a neutral, not too emotional way. Calmly acknowledge what the child said, and carry on with what you were doing together.

As SM is an anxiety disorder, the ADIS seems particularly relevant. The ADIS assesses anxiety, mood, externalizing, tics, substance use and pervasive developmental disorders according to the DSM. Very useful is a "feelings thermometer" that allows the child and parents to quantify the severity of anxiety symptoms and interference with the child's functioning. Anxiety ratings are used to assist in diagnostics. Further, they can be used for self-monitoring (in older children) and parent-monitoring of anxiety, and to assess response to treatment over time.

Younger children may be able to use simpler visual models such as hand drawn or printed smiley and upset faces. An example of a *talking map* for the school situation for younger children can be found below. Depending on age, one can ask the child to point or to draw stars in situations they do talk. One can also use colorful post-it notes: green for talking, yellow for non-verbal communication, and red for muteness. Older children can also construct their own talking maps, such as listing people they talk to, and people they will work on being able to talk to in different settings. Clinicians need to be creative to engage the child in the process.

EXAMPLE OF A TALKING MAP FOR YOUNGER CHILDREN, SCHOOL VERSION

The talking map is helpful in the assessment of selective mutism. Depending on the age, one can ask the child to point or draw stars in situations they do talk, or use colorful post-it notes, for example green for talking, yellow for nonverbal communication, and red for muteness. The map can provide information on how the child views their speaking behavior in different situations. It can also be used to evaluate change over time.

Child's name:_____Age:_____

Who helped to complete the map_____Date_____

On the way to school

In the classroom

In a small group

Alone with teacher or other adults (who?)

In other rooms at school

During meals

Out during recess

Rating scales

General

Several rating scales for anxiety symptoms are available (see Chapter F.1 of the textbook). The free to use *Revised Children's Anxiety and Depression Scale* (RCADS) includes a screening item on speaking behavior:

Item 38. *My child feels afraid if he/she has to talk in front of the class*.

The response alternatives are "never", "sometimes", "often" and "always" and a user's guide is available at the website.

Selective mutism questionnaires

The most widely used standardized questionnaires were developed by Lindsey Bergman and are included in her recent manual for the treatment of SM (Bergman, 2013). A parent version, *The Selective Mutism Questionnaire* (Bergman et al, 2008) and the teacher rated *School Speech Questionnaire* (Bergman et al, 2002) are available free at this website. Versions in other languages are available by contacting the author.

Example items from the *Bergman School Speech Questionnaire* (teacher rated)

- Item 3. *When called on by his/her teacher, this student answers verbally.*
- Item 4. *When appropriate, this student asks you (the teacher) questions.*

(Rating options are: always, often, seldom, never)

Although an overall score can be obtained by adding the ratings as an expression of the severity of the mutism, these questionnaires are quantitative measures of severity only, there is *no diagnostic cut-off score*. Diagnosis should be based on the clinical examination. SM questionnaires are helpful in the assessment of SM symptoms before, during and after treatment. In the parent version ratings are made for three different settings: school, home, and in social situations outside school. Overall subscale scores and a total score can be obtained. The teacher version rates speaking behavior in the school as assessed by the teacher.

The *Social Communication Anxiety Inventory* (S-CAI) by Elisa Shipon-Blum highlights the variety of SM behaviors by increasing the response options: non-communicative, nonverbal, transitional and verbal stages (see example items for the "home" situation below). A visual bridge illustrating the stages can be seen here.

TREATMENT

It is helpful to conceptualize treatment taking into account three groups of factors:

1. *Vulnerability factors* (genetics, temperament, social anxiety, behavioral inhibition, and neurodevelopmental disorders). The focus of treatment is not in changing temperament. If neurodevelopmental disorders are present, adequate help for these must be implemented at school.
2. *Triggering factors* (transitions and unexpected events such as starting kindergarten or school, migration, use of a new language). Children with SM benefit from preparation, training, and by being allowed more time to adjust to the new situation or transition, as well as from a structured environment where they know what to expect.
3. *Sustaining factors* (the behavior of the people surrounding the mute child). There are two opposite risks. One is to accept the child's

avoidance, speaking for them and accepting their inability to improve their communication. The other is to expect communication that the child is unable to meet in that situation. Although well intended, both attitudes are not helpful, increase the child's discomfort and can aggravate symptoms (see text box below).

SM is widely considered hard to treat and there are few high quality studies of effectiveness. The treatment literature has been dominated by case studies or case series including a wide array of treatment approaches reflecting to a large extent the theoretical orientation of the authors. Data are still scarce on treatment outcomes and on predictors of these outcomes. The few existing long-term outcome studies are retrospective, with little specific information about the treatment given at the clinics years ago. In 2006, a review of the psychosocial treatment literature stated with some caution that cognitive behavioral therapy was recommended (Cohan et al, 2006a). In recent years, evidence based CBT interventions especially adapted for children with SM have been developed (Klein et al, 2016; Bergman, 2013; Oerbeck et al, 2014). All advocate early intervention and, although somewhat different in design, frequency, duration, and location of treatment sessions, striking similarities exist between them and with pioneering work on the treatment of SM by British, Canadian and American groups (Johnson & Wintgens, 2007; McHolm et al, 2005; Kearney, 2010). Another Canadian group published a review of treatment for SM (psychosocial approaches and use of medication) (Manassis, 2009).

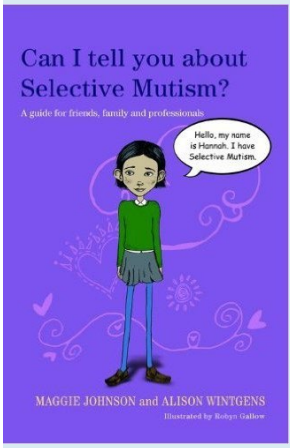
Psychosocial treatments

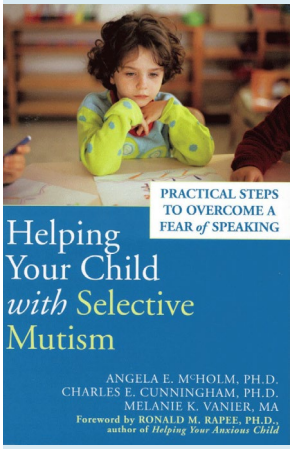
For the sake of simplicity, common key treatment factors are outlined below. Then, a brief review of the evidence about psychosocial interventions is presented and illustrated with case examples.

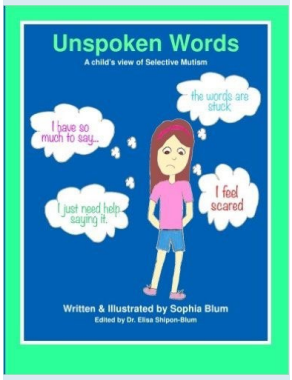
- Interventions are in general multidisciplinary and focus on decreasing anxiety, increasing social speech and ameliorating SM-related impairment
- All approaches emphasize the behavioral components of the CBT, as the symptom of mutism and the typically young age of onset make cognitive restructuring less feasible. Graduated exposure tasks and rewards for speaking behavior (reward contingency) are used
- Parental involvement is essential. Psychoeducation about SM and information on how to best help their children by reducing enabling behaviors (for instance, communicating for their mute children) and by providing communication opportunities in low-anxiety home and public situations, is mandatory. See side textbox for suggested literature to use for children with SM. See also a parental information leaflet offered by SMIRA, a British support group for SM.
- Extensive involvement of, and coordination with teachers are needed, as children with SM tend to be most symptomatic at school. Psychoeducation about SM, consultations during treatment, and simple exposure tasks at school are used.

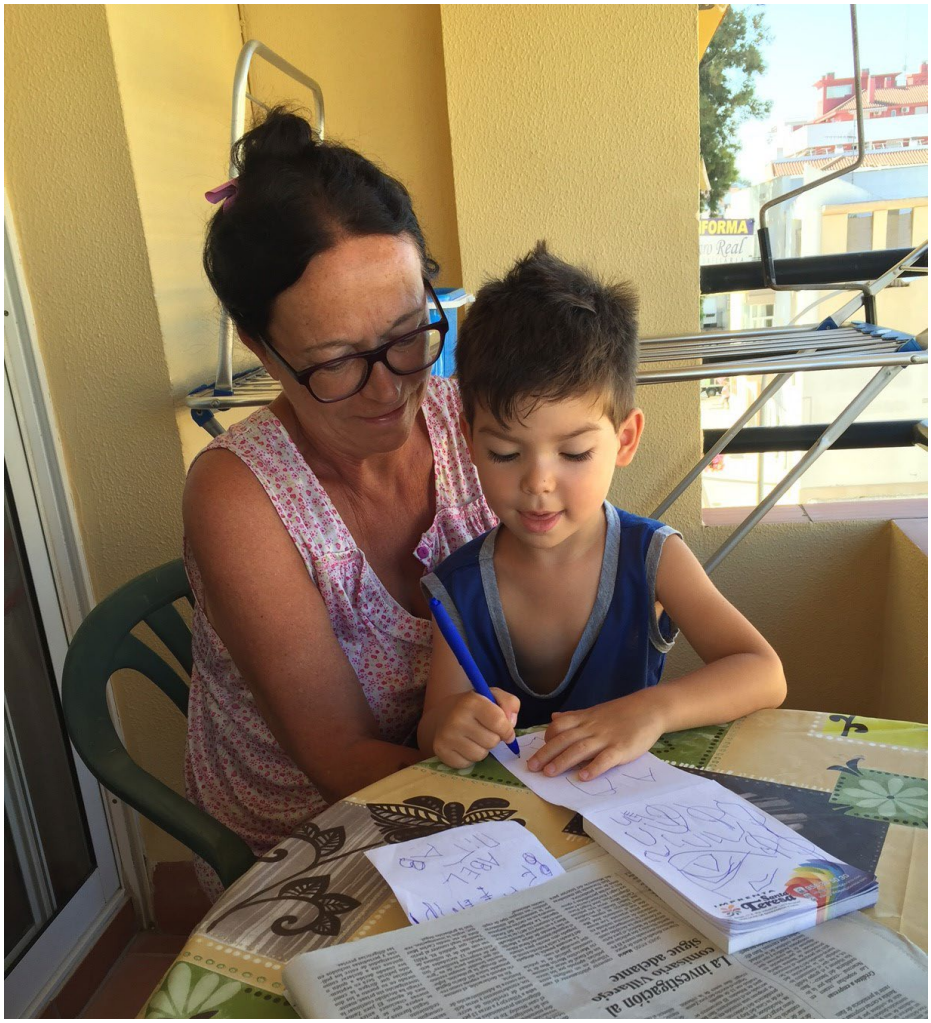
Psychoeducational resources useful for children with selective mutism and their families

(click on the image to get more information)









Suggested advice for peers

Most people are afraid of something. This child finds it hard to speak. There are ways to help him/her speak. This is how you can help:

- When someone does not speak, people can feel awkward around that person. Be friendly towards the child and try to include him/her in play activities
- Don't talk about this child being unable to speak to other people and, in general, don't speak for the child
- Don't make a fuss if the child starts to talk, just continue with what you were doing.

- As children with SM often fail to speak to the therapist, a strategy to secure early child engagement is vital. Seeking information about what the child really likes, the use of funny favorite games and play activities, and making rewards attractive are central.
- A main treatment goal is to decrease speech anxiety by reducing pressure to speak and increasing comfort by not expecting the child to look directly at the therapist. This behavior may seem like a paradoxical intervention and to work against the ultimate goal of increasing speech. However, this has been found crucial for children with SM to loosen up and engage in communication with unfamiliar people in a new situation.

The integrated behavioral therapy for SM developed by Lindsey R Bergman

This treatment is conducted at the clinic by experienced clinicians with parental participation using graded exposure tasks to the feared stimuli/situation (verbal communication) (Bergman, 2013). Therapists are in close communication with teachers to ensure relevance of exposure tasks at school. A pilot randomized controlled study including 21 children (4 to 8 years of age) found a significant increase of speech after treatment, with no change in wait-list controls (Bergman et al, 2002). Importantly, 67% of the children who received treatment no longer

fulfilled diagnostic criteria for SM and clinical gains were maintained at 3 months follow-up (Bergman et al, 2013). Diagnostic comorbidity was not assessed but significant reductions were found in social anxiety symptoms per parent but not per teacher report. See Appendix F.5.1 for an overview of the 20 sessions in the Bergman treatment approach.

Bergman's manual provides forms and charts helpful in the assessment and treatment of SM, including suggested exposure exercises. Structured assignments, planned rewards, outcome description and the rating of child's feelings are highlighted. See Appendix F.5.2 and F.5.3 for examples. Click here to access resources that you can download from the manual.

The Social Communication Anxiety Treatment (S-CAT) developed by Elisa Shipon-Blum

This treatment is also conducted at the clinic with parental participation using graduated exposure tasks and consultation with teachers to ensure understanding of SM and relevance of exposure tasks at school. The therapy consists of nine 3-weekly sessions employing extensive transfer of control to parents between the sessions to promote generalization of therapeutic gains. S-CAT incorporates behavioral and cognitive strategies to help children communicate socially within a framework of verbalization stages (see Appendix F.5.3) that become increasingly demanding, using the *SM-Social Communication Comfort Scale* (a detailed description can be found here).

A pilot study without a control group of the S-CAT program, which included 40 children with SM aged 5 to 12 years, found a significant increase of speech as rated by parents. Low SM symptom severity and high family therapy compliance were associated with better outcome (Klein et al, 2016). A detailed description of Shipon-Blum's S-CAT program is available here.

A mother's question

My daughter M. is 8 years old and in second grade. She was always very shy, speaking only to my husband and I, my son, her grandparents and some aunts and uncles. Today she speaks to everyone in our immediate family. In school she would only speak to her gym teacher privately. We have been seeing a therapist for over a year now. […] The therapist and I are trying to educate M's teachers on SM. I've been bringing her in early before any kids get in and sometimes M. will read some words to her teacher. I also taped her oral book reports for her teacher to hear. M has one very good friend that she will speak to in school. She feels very comfortable with this friend and because of her has been able to make new friends and join after school activities. Her teachers, especially the gym teacher, feel that M. is using this girl as a crutch. They want to separate them next year. I am totally against this because M. is less anxious around this other girl. I know how frustrating it is when you don't get any communication. I think her teacher probably thinks she can cure M. by keeping her away from her friend. But I think keeping M. with kids she feels comfortable with can only help her. They seem to think she needs to have other friends. M. does have other friends she just can't initiate friendships on her own.

My question to you is, "Should M. be separated from the only girl she can comfortably talk to?"

What do you think? Find one answer here.

Greta

Greta was a 5 year old girl with SM from age 3, when she began attending kindergarten. She was bilingual with mutism present in both languages. Her adolescent brother was still suffering from SM despite a long contact with mental health services.

When introducing the exposure tasks during the three home visits, Greta started to talk to the therapist in the second session, when they played her favorite game. She continued to talk to the therapist when the treatment was continued in a separate room in the kindergarten. She was eager to participate in making a ranking list of persons who should be invited in, preferring to start with peers. Interestingly, the first peer she invited was a shy, timid girl—Greta told the therapist that her friend also needed this speech training!

After 6 weeks, Greta began to whisper to peers outside the training room, and during the following 2 weeks she started to talk freely to peers and adults. At follow-up 5 years later, she still spoke in all situations and had no symptoms of social anxiety.

The home and school based intervention for SM by Hanne Kristensen and her group

This treatment starts at home, where the child feels safer and is more likely to start talking and extends to school where the symptoms are more severe. This treatment approach could be particularly useful in rural areas or where access to expert clinics is lacking. A teacher or another key person may carry out the intervention under supervision from a clinician. See Appendix F.5.4 for an overview of the home and school based intervention.

A favorable outcome was found in a pilot study of seven preschool children diagnosed with long standing SM (mean 20 months) (Oerbeck et al, 2012). Six of the seven children spoke freely in all preschool settings after a mean of 14 weeks treatment, and still did at the 1.5 year follow-up. In a randomized controlled study including 24 children with SM (age 3 to 9 years), we found a significant increase of speech after three months of treatment, with no change in wait-list controls (Oerbeck et al, 2014).

A follow-up study of 24 children 1.5 years after a six-month treatment program showed no decline of effect. On the contrary, there was a small but significant increase in speaking behavior over time (Oerbeck et al, 2015). Younger age at the start of treatment and less severe SM symptoms were associated with better outcome. A long-term follow up of 30 of 32 children (aged 3-9 years) who completed this program in Norway showed that, according to parents and teachers, 21of 30 children no longer fulfilled diagnostic criteria for SM. Four children still suffered from SM and five showed partial remission (e.g., they spoke in some but not all school situations) (unpublished data).

Pharmacotherapy

The use of medication in children with SM is largely "off label" due to the paucity of empirical evidence; medication should be considered only in very special circumstances. Currently there are two small blind trials, one for fluoxetine and the other for sertraline (Manassis et al, 2016). Medications used are largely based on extrapolating results from the treatment of other anxiety disorders. It is important to acknowledge this reality and to explain the rationale for using medication—e.g., lack of response to psychological treatment, the strong link between SM and social anxiety disorder (Compton et al, 2014). This often makes families wonder if it is worth risking the potential adverse effects of medication. However, the risk of deterioration in social and academic functioning can be high when SM is not effectively treated, and medication has the potential to improve these functional outcomes (Manassis & Tannock, 2008). If anxiety decreases with medication, some children may progress more quickly with psychosocial treatment. It is also reassuring to families if one indicates that medication response (positive or negative) and side effects will be monitored closely, and there is a plan for discontinuing medication once the child is speaking normally in most social settings.

When may medication be useful in SM?

In the case of Ellen, the child's symptoms persisted for over two years despite four months of intensive psychosocial treatment. An attempt at a "fresh start" with

a change of school had failed and her social functioning was clearly deteriorating. These events seemed to justify the use of medication. However, the question of when to use medication in SM is not easy to answer (see also video clips #3 and #4. When deciding whether or not to recommend medication, several factors must be considered:

- The limited evidence of effectiveness and potential side effects, particularly in pre-pubertal children
- Medication should be used in concert with psychosocial treatment, not as a monotherapy
- It must be clear that the child is failing to respond to psychosocial treatment alone and that symptoms are severe and handicapping. There is some debate as to how long psychosocial treatment should continue before adding medication but most authors suggest several months
- Because older children appear to have a lower rate of response to psychosocial treatment than younger ones (Oerbeck et al, 2015), medication may be considered earlier in older children. Medication may also be considered earlier in locations where psychosocial treatment is not readily available.

Click on the pictures to view the documentary (*Help Me to Speak*) that follows two children with selective mutism. Part 3 (above, 14:05) and part 4 (below, 13:11) illustrate aspects of the psychological and pharmacological treatment.

Ellen

Ellen was a 6½ year old girl when first assessed. She had migrated to Europe with her family from Southeast Asia when she was three years old. At home she was fluent in both the local language and her native tongue. Ellen was described by her parents as quiet and shy throughout her life but otherwise seemed to have developed normally. When starting kindergarten, she was completely silent at school but her teacher was pleased to have a compliant, non-disruptive child in her class. She reassured the parents that Ellen would probably participate nicely once she adapted to her new environment. However, Ellen did not speak at school that year or the next year.

Ellen was referred for mental health assessment at the end of first grade because, given her silence, the teacher had difficulty evaluating her academic progress. Ellen was diagnosed with SM. Non-verbal communication with peers was observed, resulting in some friendships. She was often included in games with her peers and several of them spoke on her behalf in class. The assessing clinician suggested behavioral therapy to encourage speaking. Her family was convinced that a "fresh start" at a new school the following September would solve the problem, so the suggested interventions were not pursued.

At her new school, in grade 2, Ellen still did not speak. Moreover, she had lost contact with peers from her previous school and was bullied at the new school. She became increasingly withdrawn, putting her head on her desk for most of the school day without looking up. The school arranged for a speech pathologist to work with Ellen and introduced a behavior modification program shown to increase speech in similar cases but 4 months later there was no progress. A second mental health assessment was done—Ellen was then 7½ years old—and medication was recommended. Seeing their daughter's deterioration, the parents were now willing to consider this option.

Fluoxetine 10mg per day was started. Ellen tolerated the medication without side effects. Six months later, she was noted to be smiling more but not yet speaking despite further work with the speech pathologist and continuing in the behavioral program. Dosage was increased to 15mg per day (20mg and 10mg capsules in alternative days). Within three weeks, she started whispering to peers. After a further month, she started speaking with the teacher if seen in private. Ellen continued on medication and was also allowed to continue with the same teacher in Grade 3 resulting in the development of normal social speech, friendships, and good academic progress that year. Medication was tapered soon after the start of Grade 4, as Ellen continued to speak normally in all environments.

As in many other child psychiatric conditions where studies of optimal dosage are lacking, the general rule for prescribing in SM is "start low and go slow"

- The clinician must weigh the potential risks and benefits of medication in a given case and help the child and family understand these as well.

Choice of medication

Fluoxetine is the best studied though there are some reports for other selective serotonin reuptake inhibitors (SSRI's) and also for two monoamine oxidase inhibitors (MAOIs): phenelzine and moclobemide (Manassis et al, 2016). The use of MAOIs in children is to be avoided given the potential side effects and foodstuffs interactions. We recommend starting with fluoxetine and switching to sertraline if there is poor tolerance or lack of response.

How should medication be prescribed?

Younger children (under age 7 or so) may start with 5mg of fluoxetine per day, either in liquid form or (if not available) by taking a 10mg capsule every other day. Due to its long half-life, the dosage of fluoxetine can be titrated by adjusting the number of capsules taken per week. If switching to sertraline, 12.5mg per day could be prescribed initially (i.e., half a 25mg capsule). As in the case example of Ellen, dosage adjustment may be needed because children vary widely in their medication needs and tolerance.

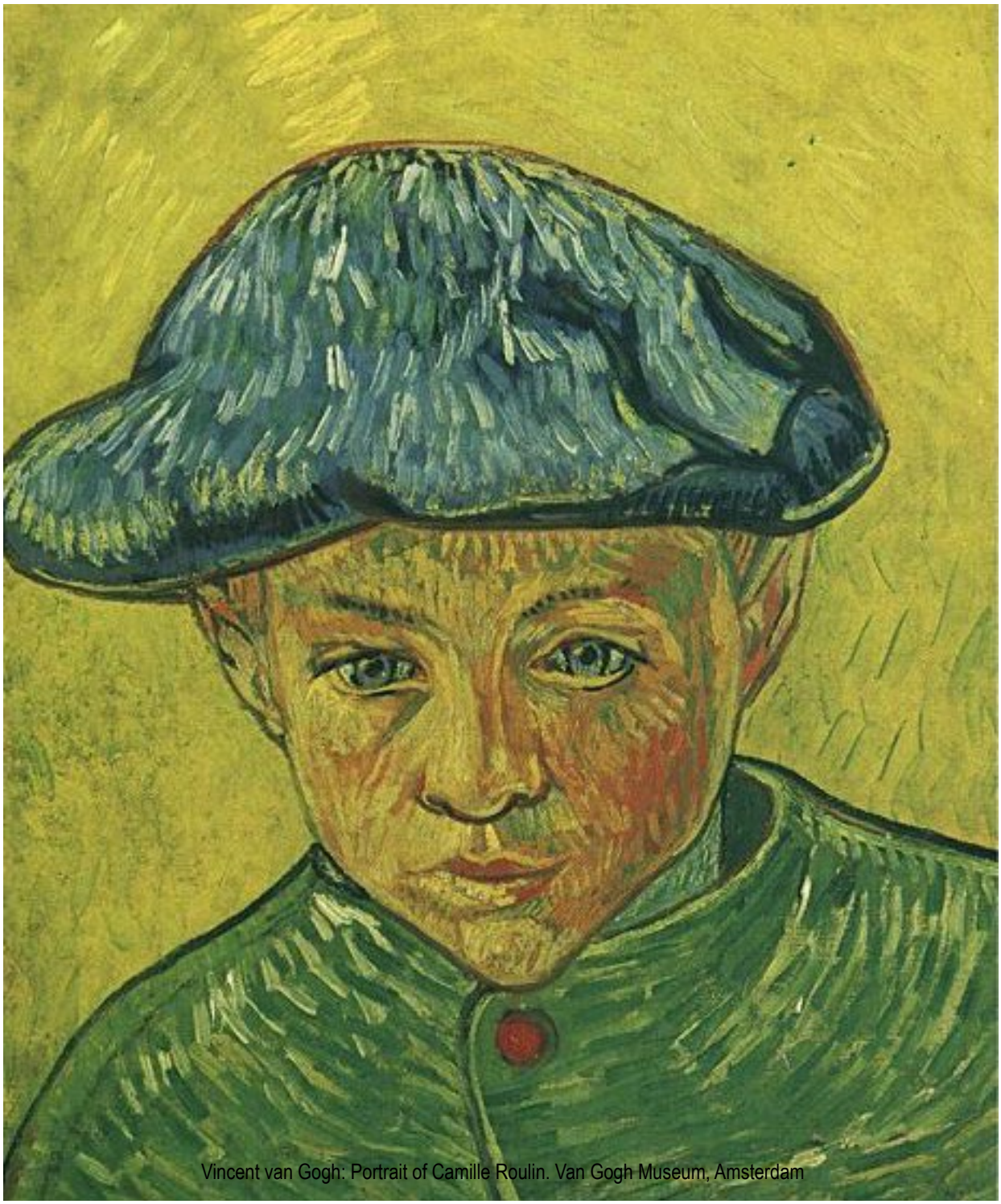
It is prudent to monitor the child's weight, which is sometimes affected by medication-related nausea, especially early in treatment. Behavioral activation, a SSRI adverse effect, is not uncommon in children (Strawn et al, 2015); it may require a reduction of the dose or change of medication. The possibility of an increase in suicidal behaviour, although uncommon (Bridge et al, 2007), should be mentioned to the family and appropriate steps put in place to ensure safety. When evaluating benefit, it is important to obtain information from teachers as well as parents, and from the child once communicating a little. When medicated, improvement is often not noted in the home environment, where symptoms are typically less severe, but is more noticeable at school. Improvement can take time: typically two to four weeks at an optimal dose, but often several more weeks before change translates into more appropriate verbal communication. Regular follow up, e.g., every couple of weeks, is ideal in order to monitor for adverse effects, adjust dosage, and continue with psychosocial treatment.

Once the child is progressing with social speech, it is important to maintain medication for a few months to optimize the benefits of co-occurring psychosocial treatment, allow children to build confidence in their new social abilities, and avoid setbacks

Tapering off medication over the summer vacation is usually not advisable, as the start of school in autumn is often a challenging time for children with SM, sometimes prompting relapse. Nevertheless, when the child speaks normally in most social settings and has established good social and academic functioning, clinicians should taper off medication. Usually, this is done by reducing dosage, waiting for a few weeks for the re-emergence of symptoms, reducing dosage further and waiting again, and then stopping medication if the symptoms do not recur. If symptoms do recur, medication is increased to the lowest previously effective level. Then, medication dosage can be re-evaluated every six months or so, ensuring that the child continues on the lowest dosage needed. The risks and benefits of long-term medication use are unknown.

CULTURALLY SPECIFIC ISSUES

The boundaries between normality and pathology vary across cultures. Hence, whether a behavior is considered problematic will differ. The threshold of tolerance for situational muteness varies across cultures, social settings, and families. However, for SM—that is, in terms of the disorder itself—just about all cultures (even those where shyness/reticence is considered a positive quality) would consider the behavior aberrant and parents would want help to improve their child's functioning.



Vincent van Gogh: Portrait of Camille Roulin. Van Gogh Museum, Amsterdam

In our opinion, the cultural issues that demand most sensitivity in relation to SM have to do with treatment:

- Internationally, there is variation about the importance placed on children's ability to present orally at school. Also varying is the amount of pressure considered acceptable when helping a child to increase speaking behavior
- In the delivery of psychosocial treatment, it varies from country to country whether health personnel are permitted or willing to help children at home or at school
- Concerning pharmacotherapy, there is great variation in how readily people are willing to use medication for SM. In many countries, such treatment is considered "off label"—meaning that physicians prescribe it without official approval from health regulators, usually because there is not enough evidence of effectiveness.

KEY POINTS

- SM is a relatively rare childhood disorder that causes significant impairment of social and academic functioning
- The cardinal symptom of SM is a consistent failure to speak in specific settings (e.g., school, social situations) despite speaking normally in other settings (e.g., at home)
- SM runs in families and is associated with the temperamental trait behavioral inhibition
- Comorbid conditions are prevalent, especially other anxiety disorders and neurodevelopmental disorders, and it is important to assess the child for these
- Assessment requires experience, sensitivity, and detailed information from parents and teachers as well as evaluating the child
- Psychoeducation and behavioral management are usually the first steps
- A structured treatment approach focusing on gradual exposure to the feared task (speaking) with reward contingency is the treatment of choice
- Medication may be useful when there is no, or partial response to psychosocial treatment. Medication can be considered earlier where psychosocial treatment is not available
- If at all possible medication should be used in concert with psychosocial treatment for SM, not as a monotherapy
- Currently, no medication is approved for children and adolescents with SM. However, a growing number of studies suggest cautious optimism regarding SSRIs
- If left untreated, SM is associated with a higher risk for other psychiatric disorders, especially anxiety disorders, as well as continued impairment in social and academic functioning.

- Do you have questions?
- Comments?

Click here to go to the Textbook's Facebook page to share your views about the chapter with other readers, question the authors or editor and make comments.

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Appendix F.5.1

Overview of the 20 sessions in the Bergman Integrated Behavioral Therapy for children with selective mutism

	TOPIC	CONTENT
1	Introduction	Overview of treatment and begin to increase the child's comfort with the new situation
2	Feelings chart, reward system	Introduce and practise using the "feelings chart," a developmentally friendly, subjective distress measure. Introduce child and family to the use of a behavioral reward system to reinforce speaking behavior and help them to develop a tailored system
3	Class list and hierarchy building	Gather details about child's verbal behavior in class. Construct a "talking ladder" or hierarchy (graded list of situations involving verbal communication that the child will be working on)
4	Exposure practice*	Review rationale behind exposure interventions and begin with in-session exposures that guide future in and out of session exposures
5-9	Initial (mild) exposures*	Develop, execute, and assign exposure exercises for situations where the child has difficulty speaking in-session and elsewhere (school, extended family, community, etc.)
10	Treatment midpoint session	Focus on review of progress to date and solve obstacles to success (e.g., teacher or parent non-compliance, problems with reward program, lack of generalization, child's oppositionality)
11-14	Intermediate (moderate) exposures*	Continue working on exposures from child's hierarchy ("talking ladder") with input from family and teachers
15	Continued exposures* and introduction of transfer of control	Continue exposure tasks and introduce the concept of transfer of control whereby responsibility for ongoing work is handed over to parent and child. Begin to elicit ideas from parent/child for out of session exposures
16-17	Advanced exposures and additional focus on transfer of control	Routinely working on more advanced exposure tasks and more focus on transferring control and responsibility for treatment to family as well as teacher if appropriate
18-19	Review of progress; advanced exposures and transfer of control	Recognize areas where progress has occurred and identify situations where difficulty speaking remains. Develop strategies to continue working in these areas, particularly if functional impairment remains. Allow family and teacher to offer suggestions of exposure tasks to target remaining symptom areas
20	Relapse prevention and graduation	Present child with progress chart to acknowledge and reinforce gains. Develop list of remaining challenges and together brainstorm ideas to continue working on these areas. Review relapse prevention strategies. Present graduation certificate and, if time permits, have small celebration

* When appropriate to the developmental level of the child, simple cognitive restructuring techniques can be added during these stages of the intervention

Appendix F.5.2

Example of a form used to conduct a structured assignment according to the Bergman manual

Assignment:

Reward expected:

Outcome: [1] Not attempted - not possible
[2] Not attempted - child did not tolerate it
[3] Attempted not completed
[4] Completed as assigned
[5] Completed with modifications

Child's rating after exposure (from 1-5; varying intensity of smiley and upset faces)

Check here _____ if child rating not obtained.

Explain outcome:

Appendix F.5.3

Stages in the SM-Social Communication Comfort Scale (Elisa Shipon-Blum)

Stage 0: Child does not respond or initiate (seems frozen)

Stage 1: Child communicates using nonverbal (non-spoken) communication and responds or initiates by pointing, nodding, gesturing, writing, or making non-speech noises

Stage 2: Child is transitioning into verbal (spoken) communication and responds or initiates responses by making sounds or using a verbal intermediary that may include whispering or using a recording device

Stage 3: Child communicates by speaking and responds or initiates using words in their typical, quiet, or altered voice from a rehearsed script or spontaneous speech.

Appendix F.5.4

Overview of the home and school based intervention for SM, by Hanne Kristensen and her group

- ***One pre-treatment psychoeducational session is held with parents and teachers together.***

  Selective mutism often gives rise to etiological speculations (e.g., the child deliberately withholds speech or is a result of trauma). This session is important to ensure a common evidence based understanding of SM, and how to best help the child.

- ***Three weekly home-based sessions with the child and parent(s)***

  Session 1. Explain (adjusted to child's age) the purpose of the visit, that other children also struggle with inability to speak outside home, that most do not know why, and that they really want to speak but don't know how to do it. Explain that it is possible to improve by practicing in small steps, that they will be prepared for what to do and receive small gifts for speaking. Introduce a work-book (talking map, stickers, drawing sheets) and an audio-tape (to play with and hear their sounds/voice), both for optional use and as a tool to enhance rapport. Choose together a favorite game—with speech demands (e.g., counting, naming)—as well as favorite rewards. Show the child how this game (exposure task) will be conducted in the 2nd session in easy and more difficult stages (see session 2).

  Session 2. Review session 1 and check the workbook/audiotape if these were used between sessions. Carry out the planned exposure task in six stages with increasing difficulty: (1) parent and child play a game; with the therapist outside the room and the door closed; (2) therapist outside the room with the door open; (3) therapist visits the room during the game; (4) therapist in the room, not playing; (5) therapist sitting beside but not playing; (6) therapist participates in the game with child and parent.

  Session 3. Review session 2 and continue the exposure task from where the child left off in session 2. Prepare the child for the next sessions to be conducted at school using the same exposure task and play material, initially accompanied by the parent (s), then training with teacher (s).

- ***17 weekly school sessions*** (if possible divide into two 30 minutes sessions to keep the child "warm"):

  Similar content as in sessions 2-3 but in another location (school). The program follows six modules with predetermined and increasingly difficult goals (see below). Children with SM can be described as starting at level zero (not speaking to adults)

Goal	
1	Speaks to the therapist in a separate school room with parent present
2	Speaks to therapist in a separate school room without parent present
3	Speaks to one teacher in a separate school room with therapist present
4	Speaks to other teachers (and children) in a separate school room with therapist present
5	Speaks to teachers (and children in some settings without therapist present (speaks to some but not all teachers; speaks in some but not all groups at school)
6	Speaks to teachers (and children) in all settings without therapist present (normal/near normal speech)