**SELECTIVE MUTISM:**
10 Years of Observations as an OT and a Parent, and Implications for Occupational Therapy

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**Handout note**

- Pictures and personal information are removed from the handout materials for confidentiality.
- There will be photos and more personal information and examples given during the presentation.
What is Selective Mutism (SM)?

• Selective Mutism is a complex childhood anxiety disorder characterized by a child’s inability to speak and communicate effectively in select social settings, such as school. These children are able to speak and communicate in settings where they are comfortable, secure and relaxed.

- Dr. Eliza Shipon-Blum, SMart Center

History

• Aphasia voluntaria 1877
• Elective mutism 1930s
• Selective mutism 1994
Diagnostic criteria for 313.23 Selective Mutism

Difficulty with diagnosis

- Almost 70% of children with SM are not diagnosed accurately or referred by their primary care physicians.
- Even when symptoms were generally very apparent and parents had expressed concern
How does SM look?
Different in different settings

Aren’t they just really shy?

<table>
<thead>
<tr>
<th>Shyness</th>
<th>Selective Mutism</th>
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<tbody>
<tr>
<td>• Warm up time is slow</td>
<td>• Warm-up time is MUCH longer than expected</td>
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<tr>
<td>• Can respond with a nod or small smile</td>
<td>• Cannot respond at all - may appear frozen</td>
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<tr>
<td>• Consistent temperament – quiet and reserved</td>
<td>• Different in different settings – restrained at school and talkative at home</td>
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</table>
 Aren’t they just being manipulative?

They can be terrified, frozen, speechless. Avoidance behavior may appear oppositional. Children with SM are found to be LESS oppositional. Examples: soiling, broken arm & waiting to tell parent

Won’t they just grow out of it?

• Even if the child starts to talk, anxiety may persist & life-long difficulties are possible.
• Delayed treatment makes for more entrenched patterns.
• Social implications – younger kids are usually accepting, older kids can be really mean, tease.
Long term risks

• 60% kids with SM continue to struggle with self-confidence, independence, achievement, and social communication skills as adults.
• Adults continue to report social anxiety

Concerns of abuse

• It was once believed that SM is caused by abuse, trauma or neglect - NOT TRUE. Parental concerns of false accusations can delay treatment.
• Kids with SM can be accident-prone, and have more injuries due to sensory integration issues.
Prevalance

- Selective mutism was once considered a “rare” childhood disorder. Prevalence rate now measured .47-.76 percent.

Increased risk for Immigrants

- Other recent research studies indicate the prevalence rate among immigrants to be over double that of non-immigrants.
Complexity of SM
It’s more than not talking

It’s important to screen for other common areas of concern:

• Social anxiety
• Language-based learning disability
• Auditory processing
• Sensory integration

Behavioral Inhibition is an inborn characteristic

• There is a familial relationship between generalized social phobia and SM
Social Anxiety

- As many as 90% of children with SM diagnosis also meet the diagnostic criteria for social phobia.

Language-based Learning Disabilities

- Although it is not believed that a learning disability causes SM, it can make SM worse by increasing a child’s anxiety, especially in school, because of the expectation to speak. Evaluation of speech and language ability is suggested.
Auditory Processing/
Sensory Integration

- Deficiencies in brain signals for auditory activity are seen in 75-90% of children with SM. Screening for auditory processing problems is recommended.

Causes

- Genetically predisposed to anxiety
- NOT caused by abuse, trauma, neglect
- Reinforcement of avoidance response to anxiety
- Other contributing factors include language and sensory integration problems
Behavioral cycle of SM

- Increased chance to repeat behavior
- Scary situation / anxiety
- Avoidance: hides, doesn't talk
- Decreased anxiety
- Reinforcement of behavior

Treatment

- Team-approach to break the cycle
- Include practical strategies
- Tailor treatment strategies per communication level (will vary depending on environment) per SM-SCCS
- Include response & initiation
- Medication is sometimes needed (SSRIs)
It takes a team

- Child
- Parent(s)
- OT
- SLP
- Psychologist
- Pediatrician
- Psychiatrist
- Teachers
- Social worker
- School administration
- Family
- Friends
- Coaches/Leaders

Practical ideas

- Responses to predictable questions and situations
- Strategies at each level of communication
The dreaded question

“Why doesn’t _____ talk?”
“_____ doesn’t talk”

_____ does talk very nicely at home. S/he will talk at school when s/he is comfortable.

How to encourage speech

- Don’t ask direct questions, except if the child looks very comfortable, then try a yes/no question.
- If you forget, and ask a question you know they’re unable to answer, answer it yourself, or say “We can decide later.”
- Give the impression you’re not overly concerned about the mutism.
- Minimize eye contact.
- Use humor/act silly/say something incorrect.
When the child does speak

“____ talks!” often accompanied by cheers, dancing, yelling

Stop all fuss immediately
“There is no need to make such a big deal - we all know ____ can talk”

Redirect attention to something new

What if the child gets separated?

• The child needs to learn full name, address, and phone number well
• Develop a plan
• Information bracelet
• Can purchase through SM-CAN
• Make own with letter/number beads
504 Plan at school

- Don’t try to force to speak, work with current communication level
- Pair with friends / buddy system
- Choose a calm and caring teacher
- Allow access to school during non-school times
- Consider toileting plan
- Email me & I will send a document

Communication levels

- Stage 0: Non-communicative
- Stage 1: Non-verbal communication
- Stage 2: Transition to verbal
- Stage 3: Verbal communication

- Communication levels include both: (a) responding and (b) initiating
- Level will be different depending on the setting and the people present
Non-communicative

- No response, no initiation
- No social engagement
- Child is too anxious and UNABLE to respond at all
- Must lower anxiety in that setting
Non-verbal communication

- Physical participation
- Proximity (standing by toilet sign, indication of desire to play)
- Nod yes/no, point, gestures, sign language (may start with finger obscured)
- Raise hand
- Writing / drawing
- Non-voice augmentative devices (communication board, symbol, photos, picture menus)

Non-verbal initiation

- The hand-over
  - The child approaches someone to hand them something
- The clock-watcher
  - The child watches the clock until a designated time & informs the teacher with a clap, bell, raises hand, etc.
The hand-over

- Money for pizza delivery
- Payment at farmers’ market / store
- Library card
- Notes to the teacher / school staff

Transitioning to verbal

- Non-verbal sounds
- Use of verbal sounds
- Augmentative devices with sounds
- Use of a verbal intermediary
Non-verbal sounds

- Clap/snap
- Whoopie cushion
- Musical instruments
- Noisy toys

Verbal sounds

These are steps in the right direction - encourage them

- Grunts
- Squeaks
- Moans
- Animal noises
  - “animal hide and seek”
  - Have the whole class answer to role call with animal noises
Augmentative devices with sounds

- Recorder in teddy bear
- One talker recorder button
- Regular tape recorders
- Talking photo album
- Small camera with short video
- Video camera

NEVER TRICK A CHILD WITH RECORDERS!

Verbal intermediary

start at lips and move out in very small increments until arm is extended

- Whisper to parent or friend
- Lil’ whisper
- Finger puppet
Verbal intermediary
increase the distance in very small steps from here ........ to ........ here

Responding verbally
• Verbal response when obscured / hiding
• Altered or made-up language
• Baby talk
• Reading / scripts
• Verbal games
Verbal games

- Sing in car (parent’s back is turned)
- “Hug bug”
- Knock-knock jokes
- “I’m thinking on an animal” game
- BINGO, Go-fish, Hi-Ho-Cherry-o, Uno, Twister, Zingo
- Walkie-talkie
- Telephone games

Telephone use

- Pretend / play telephone, walkie-talkie
- Land phone & cell phone with parent in same room, then increase distance
- Telephone hide-and-seek
- Call & speak with parent remotely
- Mystery caller (choice of 2-3 people that child already speaks on the phone)
Include a sensory diet

- Kids with SM seem to have problems with sensory integration
- Evaluate by an occupational therapist trained in sensory integration
- A child’s sensory needs changes depending on the environment (ie: needs proprioception when anxious)

Implications for OT

- Sensory integration needs
- Relaxation strategies
- Cognitive restructuring
- Practical needs
- Adaptive strategies & equipment
Sensory integration
monitored by an OT trained in this treatment

• Heavy work / proprioception
• Movement / vestibular system
• Oral motor
• Tactile
• Olfactory
• Auditory
• Neutral warmth
• Deep pressure

Heavy work

• Jump and crash on mattress
• Swimming
• Hockey
• Climbing on jungle gyms
• Pulling “garbage”
• Twister
Vestibular stimulation

- Swinging
- Bouncing
- Hammocks
- Rocking chairs

Cognitive Behavioral training

- Relaxation training (Physiological)
- Cognitive restructuring (Cognitive)
- Gradual desensitization (Behavioral)
Relaxation techniques

- Improve awareness of physical anxiety response
- Deep breathing
  - Teddy bear on stomach to monitor
  - Blow bubbles
- Muscle relaxation
  - Robots & ragdolls
- Imagery
  - Colors
  - Guided by tapes / CDs

Cognitive Restructuring

- Confidence building
  - Confidence activities
  - Power bracelets
- Challenge negative thoughts
Gradual desensitization

- Gradually increase the challenge
- “Baby steps” (we needed 7 steps from raising hand at shoulder level to straight above head)
- Rewards

Rewards

- Small immediate (brave bucks, stars, stickers) & working towards a larger big reward (ice cream, special event).
- Don’t worry that they’ll never do it without a reward. They will.
Case Studies

- Kids can overcome selective mutism with the right help
- Kids can continue to have significant life-long struggles
- It’s important to treat early, don’t “just wait and see if they outgrow it”
- It’s important to be comprehensive

Resources: Websites

- Selective Mutism Anxiety Research & Treatment Center (SMart Center): http://www.selectivemutismcenter.org/
- Child Mind Institute: http://www.childmind.org/
- Selective Mutism Group ~ Childhood Anxiety Network: http://www.selectivemutism.org/
- American Speech-Hearing Association: http://www.asha.org/
Webinars

- Selective Mutism: Your Resource to Understanding a Child with SM (self-paced) 3 hours
- Assessment and Treatment of Children with Selective Mutism (self-paced) 2.5 hours

Professional Contacts

- Caroline Portoghese, OT
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- Sarah Pavek, Psychologist
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- Becky Lulai, SLP
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Parental contacts

- Beth Olson, Parent
  olsons591@AOL.com
- Lisa Lehmann, Parent
  lehmann5@comcast.net
- Caroline & Becky (from previous slide) are also parents of kids who once suffered from SM

- Paul McCartney video: “She’s Given Up Talking” http://www.youtube.com/watch?v=0dNfUoum9k
References


Shipon-Blum, E. SM-Stages of Communication Comfort Scale. Smart Center, Philadelphia, PA.


THANK YOU

Thanks for your time and interest.
Professionals and parents may contact me
with questions or for support.
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