Name: Marliz T Khames | DOB: 6/8/2016 | MRN: 040915167 | PCP: Allison Oldacre Griffin, DNP | Legal Name: Marliz T Khames



Vanderbilt Children's Developmental Medicine - Beechwood 2416 21st Ave S Suite 300 Nashville TN 37212

Mrliz Khames

Developmental Medicine Pediatric Developmental Telemedicine Consultation

Patient Name: Mrliz Khames Date of Visit: 4/22/2020

PCP: Allison Oldacre Griffin, DNP

Referred for Consultation by: No ref. provider found

Chief Complaint:

Mrliz is a 6 y.o. 0 m.o. female who presents with her mother for consultation about a possible autism spectrum disorder.

This consultation was provided via telemedicine using two-way, real-time interactive telecommunication technology between the patient and the physician. The interactive telecommunication technology included audio and video. The patient was offered telemedicine as an option for care delivery and consented to this option.

Patient location: LaVergne, Tennessee

Provider located at Vanderbilt University Medical Center, Nashville

Other participants present with provider, with patient's verbal consent: none

Other participants present with patient: mother

Subjective

HPI:

Mrliz is a 6 y.o. girl who presents for consultation regarding a possible autism spectrum disorder. There have been concerns about her development since she was 12-18 months of age, primarily due to language delays. As she has aged, concerns about her language have persisted. Her family has also noted that she has some atypical behaviors (e.g. challenging behavior, sensory differences) and struggles to interact with other children. Due to developmental and behavioral concerns, she was referred to the Center for Child Development for an autism spectrum disorder evaluation.

Motor:

She walked at 12 months of age. Currently, she can run, jump, and climb, without balance or coordination issues. She talks on her tip-toes when she is playing.

Verbal Communication:

She has a history of speech-language delay. She did not have a period of speech-language regression. She started talking between 2 and 3 years old. Currently, she communicates using phrases. Her speech can be difficult to understand. She still physically directs others (e.g., hand as tool). She frequently echos her mother's speech. She frequently quotes from YouTube videos. Receptively, she understands most of what is said to her. She inconsistently responds to her name being called. She responds 5% of the time, per parent report.

Nonverbal Communication:

Her use of eye contact is very poor ("zero" per parent report). She does not integrate verbal and non-verbal communication. She rarely uses communicative gestures. She does not point. Rather, she grabs her mother's hand and guides her to a desired object. She does not understand gestures used by others. She cannot read the body language of others. Her facial expression doesn't always reflect her emotional state. She is often hard to read, per parent report.

Social Emotional Reciprocity:

She has an atypical social approach. She cannot have normal back-and-forth conversation. She rarely shares her interests with others. She does not initiate social interactions. She would likely not respond to social interactions.

Relationships/Play:

She does not show interest in her peers. She does not play interactively with other children aside from her older sister. Rather, she just pushes other children. She does not have reciprocal friendships, per caregiver report. Her favorite play activity is playing outside. She does not like enclosed areas. She plays functionally with toys. She does not engage in imaginary or pretend play.

Routine/ Rigid Thinking:

She has an insistence on sameness. She inflexibly adheres to routines. She wakes up and goes outside every morning. She would become very upset if she could not go outside. For example, she has a difficult time on a rainy day. When frustrated, she hits herself on the head or bangs the back of her head. She has trouble transitioning away from preferred activities.

Restricted or Atypical Interests:

She does not a history of highly restricted, fixated interests that are abnormal in intensity or focus.

Sensory:

She is hypersensitive to auditory stimuli. She food texture aversions (e.g, soft textures such as yogurt). She does not have clothing texture aversions. She lays on the floor and watches her toys. She has a history of mouthing or licking non-edible objects (e.g., paper puzzle pieces). She smells foods before she eats them. She is interested in her shadow and reflection. She loves bright lights, such as disco lights.

Stereotypies/ Repetitive Behaviors:

She does not have a history of stereotyped or repetitive movements. She has a history or stereotyped use of objects (e.g., lining up toys). She organizes toys by color. She has a history of stereotyped or repetitive speech (e.g., echolalia, stereotyped speech).

Attention/ mood/ behavior:

Her attention span is variable based on her interests. Her activity level is high. Her mood is described as generally happy, but emotionally reactive. She has temper tantrums. She is regularly aggressive towards others. She engages in self-injurious behavior (e.g., hitting self, banging head).

Sleep:

She sleeps well.

Eating:

She is a picky eater and has food texture aversions. She eats fewer than 20 foods. She likes fries, pizza, macaroni. The only fruits she will eat are apples and watermelons. The only vegetables she will eat is onion and red peppers.

Toileting:

She is not toilet trained. Her mother has attempted toilet training, but does not feel that Marliz is making good progress.

School/Interventions:

- School: No
- Outpatient Therapy: none reported
- Past Evaluation(s):
 - Audiology Evaluation, 3/24/2018, normal hearing

Review of Systems:

General: No concerns about growth, fatigue, malaise.

Ophthalmology: No concerns about vision or strabismus. Vision testing normal.

Otolaryngology: No hearing concerns. Normal hearing evaluation. No episodes of recurrent otitis media.

Dental: No concerns.

<u>Cardiac:</u> No murmur, cyanosis, syncope, chest pain, or exercise intolerance.

<u>Pulmonary:</u> No chronic cough, wheezing, or respiratory infections.

Feeding/Diet/Nutrition: No problems with chewing, choking, or swallowing.

GI: No chronic vomiting, diarrhea, or constipation.

<u>GU:</u> No chronic problems with urinary stream, pain, or infection.

Orthopedics: No concerns about bones or joints.

<u>Neurology:</u> No history of seizures. No unusual staring spells associated with decreased responsiveness, tics, or muscle tone abnormalities.

Dermatology: No rash or birthmarks.

No past medical history on file.

No past medical history pertinent negatives.

No past surgical history on file.

Birth History:

Complications during pregnancy: no

Complications at delivery: no

Full-term: Yes

No Known Allergies

Current Outpatient Medications:

 guanFACINE (TENEX) 1 mg immediate-release tablet, TAKE 1/2 TABLET BY MOUTH EVERY NIGHT AT BEDTIME (Patient not taking: Reported on 12/13/2021), Disp: 15 tablet, Rfl:

Medication History:

None reported

Family History

Problem Relation Age of Onset

No Known Problems FamilyAutism spectrum disorder Neg Hx

Social History:

Lives with: mother, sister and grandmother

Objective

Physical Exam:

Behavior: spoke in single words and phrases; speech difficult to understand; spent a majority of the play-based observation crying; did not responds to name when called by mother multiple times; exhibited extreme difficulty with transitions; observed to bang her head on the floor in frustration; observed to hit herself in the face when frustrated; observed to flap hands on two occasions; observed to use parents hand as tool to access TV

Assessment/Plan

Developmental Testing:

The **Childhood Autism Rating Scale-Second Edition** (CARS-2) is a widely used rating scale for the detection and diagnosis of autism spectrum disorder. The CARS-2 consists of 14 domains assessing behaviors associated with autism, with a 15th domain rating general impressions of autism. Each domain is scored on a scale ranging from one to four; higher scores are associated with a higher level of impairment.

Total scores can range from a low of 15 to a high of 60; scores below 29.5 indicate minimal-tono symptoms of autism, scores between 30 and 36.5 indicate mild-to-moderate symptoms of autism, and scores from 37 to 60 indicate severe symptoms of autism. The CARS-2 also allows symptom levels to be compared to other individuals with autism spectrum diagnoses through standardized T-scores (mean of 50) and percentile ranks. Raters base their ratings on observations, parent report, and relevant medical records.

Mrliz's symptom level of 33.5 (T-score = 44, 28 percentile) indicate Mild-to-Moderate symptoms of autism spectrum disorder.

Specific vulnerabilities include: verbal communication, nonverbal communication, socialemotional reciprocity, insistence on sameness, sensory differences, repetitive behaviors

Assessment:

Mrliz is a 6 y.o. 0 m.o. female who has a history of language delays and was referred or consultation regarding a possible autism spectrum disorder. Based on history and today's evaluations, Mrliz has deficits in verbal and nonverbal communication, decreased reciprocity, difficulty developing and sustaining play with others, rigid thinking, sensory seeking and avoiding behaviors, and repetitive behaviors. This is all consistent with an autism spectrum disorder with a specifier of language delays. Mrliz also has delays in multiple developmental domains (delayed milestones).

Intensive and individualized intervention, including educational programming, therapies, and behavioral supports are associated with better outcomes over time. As such, it is strongly recommended that Mrliz receive the interventions outlined below. Mrliz is fortunate to have a family who is seeking to better understand her needs and the appropriate strategies to help her progress. She will benefit from her family's good care and advocacy for her.

<u>Diagnosis</u>: Autism Spectrum Disorder Delayed Milestones

Recommendations:

- **Preschool**: It is recommended that Mrliz participate in a structured preschool to promote learning skills, provide opportunities to interact with the same-age peers, facilitate communication development, and social skills.
- **Speech Therapy**: We recommend a speech/language pathology evaluation to assess receptive and expressive language skills, as well as pragmatic language (social communication), including eye contact, turn-taking, reciprocity, play skills, and conversations. Therapy might be initiated following this evaluation.
- Occupational Therapy: We recommend an occupational therapy (OT) evaluation to assess fine motor skills, motor coordination and balance, core strength and stability, selfcare skills, and any sensory strategies that may be helpful for keeping her regulated. Therapy might be initiated following this evaluation.
- Applied Behavior Analysis (ABA)/ Behavior Therapy would likely be helpful in managing difficult behaviors, improving compliance, and providing support for improving frustration

tolerance across multiple settings. This type of therapy can also help teach interactive play and social skills.

- To address safety-concerning behaviors (e.g., self-injurious behaviors in the setting of frustration), it was determined to trial a medication called **Guanfacine**. We will start with 0.5mg once daily at bedtime. Mom will contact me after 2 weeks and let me know how she's doing on the medication, or sooner in the event of adverse effects.
- Toilet Training: Some children with developmental delays require the use of a toileting schedule to establish toilet training. These children may be inattentive to their body's cues to use the bathroom. Families can establish a routine that involves teaching a child to sit on the toilet on a timed schedule for a brief period of time, up to five minutes (sitting on the toilet for longer periods of time can make toileting more difficult). This can be started slowly if Mrliz dislikes sitting on the toilet. One should have their feet comfortably placed on a stool (with knees slightly above the hip bones) so the muscles of the pelvis can relax. An enjoyable and relaxing toilet only activity (such as books or music or another activity that he/she enjoys) can be given to cue the time for sitting and relaxing. Initially, she should be rewarded for sitting. Later, the reward can be for peeing or pooping on the toilet. This reward might be praise, food, a video, special time with a parent or another reward. Making a list of rewards that are easy to do may be helpful as rewards often need to be changed when they no longer work. Picking times to sit on the toilet about 30-40 minutes after meals, having her engage in physical activity and giving her warm liquids (tea or hot apple cider for example) may increase success for pooping on the toilet. We discussed that these strategies may take time and some tweaking.
 - The following resources may be helpful for Mrliz's toileting concerns:
 - ATN toileting toolkit: www.autismspeaks.org/docs/sciencedocs/atn/atn_air-p_toilet_training.pdf
 - ATN constipation toolkit <u>www.autismspeaks.org/sites/default/files/docs/sciencedocs/atn/guide_for_managing_co</u> nstipation.pdf
 - Toilet Training for Individuals with Autism or Other Developmental Issues by Maria Wheeler
- Genetic Testing: Autism spectrum disorder (ASD) is a neurological disorder that has many causes. A known genetic condition is found about 10-20% of the time. Eighty to ninety percent of the time, no cause can be found. It is recommended that Mrliz have blood drawn for a chromosomal microarray and DNA for fragile X syndrome. If either of these tests were abnormal, it could change management the following ways now or in the future: potential for more targeted medication or therapeutic management, assessment for medical comorbidities associated with that genetic condition, as well as assist in family planning for Mrliz and her family.
- Some families may benefit from **enrolling in Social Security Disability benefits** for their child. If you're interested, visit the following website:
 - https://www.ssa.gov/disabilityssi/apply-child.html OR
 - Call 1-800-772-1213
- **Resources**: The following resources may provide information of interest:
 - Autism Tennessee is an organization in Middle Tennessee that helps connect families to appropriate services and resources. Go to their website at www.autismtn.org You can

- find contacts for your county under the resources tab
- STEP (Support and Training for Exceptional Parents) Tennessee is a support group that
 helps families connects with resources, work with schools and offers events and training
 sessions throughout the year. This group is very helpful when learning about special
 education. Please go to their website www.tnstep.org for more information.
- The non-profit organization Autism Speaks has a 100 Day Kit that is available free of charge. It may be ordered by calling 888-AUTISM2 (288-4762) or online at www.autismspeaks.org/community/family_services/100_day-kit.php
- The Vanderbilt Kennedy Center is an organization that can provide trainings for families, school based consultation, and opportunities for participation in research programs (TRIAD). To learn more about resources through the Kennedy Center, families can call the Vanderbilt Autism Resource Line at (877) ASD-VUMC or http://vkc.mc.vanderbilt.edu/vkc/
- Groups such as Family Voices can also be contacted for information about assistance for families of children with medical and developmental disabilities. More information can be found at www.familyvoices.org.
- Tennessee Disability Pathfinder is a support group to help families navigate community services. More information can be found at www.vkc.mc.vanderbilt.edu/vkc/pathfinder/ or at 1-800-640-4636.
- Return to clinic in 3 months to gauge progress in interventions.

It was pleasure seeing Mrliz and her family in clinic today. If you or your primary care provider have any questions or concerns, please call us at 615-936-0249.

Allison O. Griffin, DNP
Pediatric Nurse Practitioner
Monroe Carell Jr. Children's Hospital at Vanderbilt University Medical Center

Patient (Mrliz Khames)

DOB(6/8/2016)

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