

The logo for 'prisms' features the word in a bold, lowercase, sans-serif font. The letter 'i' is replaced by a vertical DNA double helix structure. Above the top of the DNA helix is a circular icon with a fan-like or shell-like pattern. A thin horizontal line is positioned below the text.

prisms

EDUCATION | AWARENESS | RESEARCH

prisms.org



prisms
2022

AUGUST 4-6, 2022

Envisioning the Possibilities

11TH INTERNATIONAL CONFERENCE | DALLAS, TX



Envisioning the Possibilities

11TH INTERNATIONAL CONFERENCE | DALLAS, TX



**prisms
2022**

*Envisioning
the Possibilities*

Managing Food Seeking Behaviors with Help from Prader-Willi Syndrome

Amy L. McTighe, Ph.D.
Educational Consultant

August 5, 2022
Session #1- 9:45-11:00
Session #2- 3:00-4:15

Introduction and Background- Amy McTighe, Ph.D.

Agenda

- Review the similarities and differences between Smith-Magenis Syndrome and Prader-Willi Syndrome
- Discuss best practices used to manage food seeking behaviors for individuals with SMS and PWS.
- Discuss training opportunities, education and support for those working with individuals with SMS across all settings
- Question and Answer session

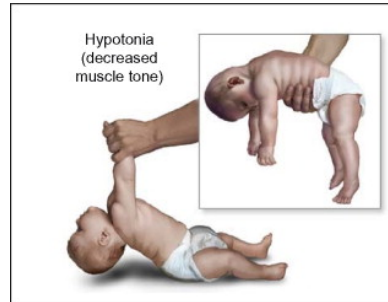
Similarities and Differences between SMS and PWS

- Both PWS and SMS are rare genetic syndromes.
- PWS is caused by a failure to receive active genes of father's chromosome **(15q11-q13)**
- SMS is caused by a genetic change on chromosomal region **(17p11.2- RAI1 gene)**
- The prevalence is a similar **(PWS 1:12, 000 to 1:17,000) (SMS 1:15,000 to 1:25,000)**

Similarities and Differences between SMS and PWS

Many common features...

- intellectual disability
- hypotonia (low muscle tone)
- poor gross and fine motor skills
- decreased sensitivity to pain
- constipation
- sleep disturbance
- excellent memory of people and places
- scoliosis
- eagerness to please and sensitivity towards others



Similarities and Differences between SMS and PWS

The most common characteristics between SMS and PWS include...

- maladaptive and self injurious behaviors
- physical and verbal aggression
- food seeking behaviors
- behaviors associated with food exposure and food related activities



Similarities and Differences between SMS and PWS

- PWS has temperamental and behavioral characteristics similar to SMS.
- These characteristics are so commonly present that they become part of the PWS behavioral phenotype. (Behavioral phenotype = PWS personality)
- Psychiatric and behavioral symptoms can be organized across five domains

(Food seeking behaviors, Cognitive rigidity/ inflexibility, Oppositional Defiance, Anxiety/ insecurity, and Skin picking/ self injurious behaviors)

Similarities and Differences between SMS and PWS

What may cause behaviors around food in SMS and PWS?

- unplanned food exposure
- thinking about food
- an upcoming social event
- change in schedule
- a change in the expected meal
- a social situation or interaction
- purposeful meltdowns with someone they know will “give in”



What do food related behaviors in SMS and PWS look like?

- overeating typical food
- eating frozen food
- food sneaking/ foraging
- manipulating to get food
- shoplifting or stealing food
- verbal/ physical aggression to obtain food
- food thinking



Managing Food Seeking Behaviors in SMS and PWS

- Food security = managing food related behaviors
- Food security = a measure of the availability of food and the individual's ability to access these foods in socially acceptable ways
- Food security is not just about keeping food out of reach
- It is also about keeping food out of sight and mind.



Managing Food Seeking Behaviors in SMS and PWS

No Doubt	No Hope	No Disappointment
<p>Predictable routine Food is scheduled Person with PWS can relax and think less about food Menu predictability reduces anxiety</p> <p>*Dr. Forster and Dr. Gourash- Pittsburgh Partnership</p>	<p>No unplanned extras outside of the schedule meal times No opportunities to gain access to food Chances to obtain food cause stress</p>	<p>Expectations are made that will be reliably carried out No other expectations have been raised so there is no disappointment when there are not realized or fulfilled</p>

Managing Food Seeking Behaviors in SMS and PWS

- Lock all areas that contain food
- Locking reassures the person with SMS/ PWS that they can't obtain the food- it is not a punishment
- Locking sets the environment up for success
- Locking food creates improved physical and mental health



Managing Food Seeking Behaviors in SMS and PWS

- Provide a structured predictable routine for meals and food exposure
 - post a menu
 - provide a written schedule that shows when the next meal will occur
 - provide the same alternative if the planned menu is disrupted
 - provide an alternative setting for scheduled mealtimes
 - plan for food exposure that is not typical
- Adult supervision should be provided during mealtimes
- Food should not be used as a reward during instruction or to obtain compliant behaviors in any setting



Managing Food Seeking Behaviors in SMS and PWS

Not observing food related behaviors?

- These behaviors don't always happen immediately!
- Behaviors could be related to “food thinking”
- Poor expressive language skills = negative behaviors



Example:

12-year-old student with SMS eating in the cafeteria
Afternoon behaviors in the classroom- physical and verbal aggression
removed him from the cafeteria = behaviors decreased

Managing Food Seeking Behaviors in SMS and PWS

What if food is accessed in the environment?



- Small portions of food = do not take food!

Large portions of food = take food and be prepared to deal with behaviors that go along with taking food

- Don't punish an individual with SMS or PWS for obtaining unlocked food.
- Philosophy is that it is the responsibility of the caregiver to lock food and provide a food secure environment.



Managing Food Seeking Behaviors in SMS and PWS (Cognitive rigidity/ inflexibility, Oppositional defiance, Anxiety/ insecurity, Skin picking/ self injurious behaviors)

- Could look like worry
- Constant need for reassurance
- Questions about schedules/ expectations
- Some physical agitation-rocking and fidgeting
- Can lead to tearfulness
- Uncooperative behaviors
- Aggressive behaviors
- Shutting down- person not responsive/ not able to be redirected



Managing Food Seeking Behaviors in SMS and PWS (Cognitive rigidity/ inflexibility, Oppositional defiance, Anxiety/ insecurity, Skin picking/ self injurious behaviors)

1. Visuals
2. Calendars
3. Social Stories
4. 3 card system
5. Re-direction
6. Prompting to complete a highly preferred activity
7. Positive behavior support
8. Provide an alternative activity to replace picking

Home Insert Page Layout References Mailings Review View

Clipboard Font Paragraph Styles

1 Normal 1 No Spacing 1 AaBbCc Heading 1 1 AaBbCc Heading 2 1 AaBbCcD Title 1 AaBbCcD Subtitle 1 AaBbCcDd Subtle Emp... 1 AaBbCcDd Emphasis 1 AaBbCcDc Intense Em... 1 AaBbCcDc Strong 1 AaBbCcDd Quote

Daily Schedule/Record of Accomplishments

Name John Bloom Date 5/17/2019 Staff: Day: Jane Evening Patrick

2 Target Behavior Goals: #1 Safe hands #2 Nice words

Goals:

8:00-10:00 X= 15

11:00-1:00 X= 15

SCHEDULES/ VISUALS/ REWARD SYSTEMS

<u>TIME</u>	<u>ACTIVITY</u>	<u>Attend</u>	<u>Participate</u>	<u>Cooperate</u>	<u>Behavior #1</u>	<u>Behavior #2</u>
8:00-8:30	BREAKFAST	X	X		X	X
8:30-9:00	Morning announcements	X	X	X	X	
9:00-9:30	Physical Therapy	X	X	X	X	X
9:30-10:00	Physical Therapy	X	X	X	X	X
10:00-10:30	Reward- Computer Time					
10:30-11:00	Occupational Therapy					
11:00-11:30	Occupational Therapy					
11:30-12:00	Free Time					
12:00-12:30	LUNCH					
12:30-1:00	LUNCH					
1:00-1:30	Reward- Computer					

Windows taskbar with icons for Internet Explorer, File Explorer, Chrome, Mail, Calendar, Word, and a clock showing 9:51 AM on 5/10/2019.

Managing Food Seeking Behaviors in SMS and PWS (Cognitive rigidity/ inflexibility, Oppositional defiance, Anxiety/ insecurity, Skin picking/ self injurious behaviors)

- **It is often impossible to stop a meltdown!**
Remain calm, think before you speak/act, speak in a calm voice. Avoid yelling! Try not to show fear, anger, or frustration.
- **Keep yourself out of harms way**
Move dangerous objects away and seek assistance from others if needed
- **Give time and space to calm**
Retreat to a designated area until calm
- **If yelling is happening, refuse to speak**
Praise when the calm voice is used/redirect.

Managing Food Seeking Behaviors in SMS and PWS (Cognitive rigidity/ inflexibility, Oppositional defiance, Anxiety/ insecurity, Skin picking/ self injurious behaviors)

- **Move past the episode!**

Do not punish or debrief the episode later in the day

“What could you have done better when you were mad earlier today?”

- **Avoid reigniting the anger or frustration**

Do not discuss it the following day

- **Never give in to unreasonable demands**

- **Let the meltdown run its course!**

When the person is calm, redirect and move on.

People with SMS and PWS are.....

HARD WIRED

- ***PWS and SMS behaviors decrease but they aren't always eliminated!***
- ***Stable behaviors do not equal cured behavior.***
- ***Supports can't be removed!***

Summary of Managing Food Related Behaviors

Behavior management with PWS is based on:

- total food security/ limited food exposure
- positive behavior support and verbal praise
- reward systems
- environmental accommodations and modifications
- preparation
- predictability
- schedules
- visuals
- thinking outside of the box about behavior and ways you manage behaviors
- determine if food security or total food security is needed

SUMMARY



Training Opportunities- Supporting Individuals with SMS

- It is essential to educate those working with individuals with SMS in all environments (e.g. schools, group homes, community agencies, etc.)
- This education supports a quality of life for persons with Smith-Magenis syndrome and provides opportunities for interaction with typical peers.

- Yearly Consultation/ training packages
(40 hours/ 30 hours/ 20 hours/ 10 hours)
- Educational training for staff (by the hour)
- Parent advocacy for school and community meetings
- Depositions and expert witness for due process hearings and legal matters

Contact Information

- Dr. Amy McTighe
Educational Consultant
(412) 600-8165
mctigheamy@gmail.com

Question and Answer Session

