

Sensory Issues and Interoception Associated with Autism

1. Range of sensory experiences
2. Effects on everyday life
3. Assessment instruments
4. Coping mechanisms
5. Emotional empathy
6. Interoception

DSM 5-TR Diagnostic Criteria

- *Hyper- or hypo reactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching objects, visual fascination with lights or movement)*



Sensory Experiences at School

- *The corridors and halls of almost any mainstream school are a constant tumult of noises echoing, fluorescent lights (a particular source of visual and auditory stress for people on the autistic spectrum), bells ringing, people bumping into each other, the smells of cleaning products and so on. For anyone with the sensory hyper-sensitivities and processing problems typical of an autistic spectrum condition, the result is that we often spend most of our day perilously close to sensory overload. (Sainsbury 2000)*

Exteroception and Interoception

- **Exteroception**

- Sensing the **outside** world
- Sound
- Sight
- Touch
- Smell
- Taste
- Emotions in other people

- **Interoception**

- Sensing the **internal** world
- Pain, illness (vomiting)
- Heart rate and breathing
- Hunger
- Digestion sensations
- Temperature
- Emotions within yourself
- Alexithymia

Prevalence

Crane et al. (2009) *Autism* 13

Sensory processing in adults with ASD

- 94% reported extreme levels of sensory processing
- Unusual sensory processing can occur **across the lifespan**
- Can be reported as early as **6-12 months**
- Was originally part of the 1980 diagnostic criteria for ASD but **not unique to ASD**, e.g., schizophrenia and ADHD

Sensory Habituation

Gandhi et al. (2021) *Journal of Autism and Developmental Disorders* 51, 2218-2228

- Nearly 90% of autistic children exhibit sensory atypicality

Jamal et al. (2021) *Journal of Autism and Developmental Disorders* 51, 3153-3164

- Sensory sensitivity does not habituate to repeated exposure
- **Clinical experience**
- Life-long problem
- Learn how to avoid the sensory experience
- Develop the ability to suppress the physiological reaction and endure the experience
- **Autistic Well-Being:** Maja Toudal Survey
- Freedom from excess sensory pain/disturbance

Changes in Sensory Processing During Childhood

Dellapiazza et al (2021) *European Child and Adolescent Psychiatry*

- 51 ASD children aged 3-10 years
- **Sensory Profile Questionnaire** at baseline and three years later
- Three subgroups
- **Stable** in 11 of 51
- **Decreased** in 14 of 51
- **Increased** in 26 of 51

Sensory Sensitivity for Adults

MacLennan, O'Brien and Tavassoli (2022) *Journal Autism and Developmental Disorders* 52, 3061-3075

- 49 autistic adults completed an online survey
- **Hyper reactive** to:
 - Loud noise (87%)
 - Lots of conversations (82%)
 - High-pitch noises (77%)
 - Bright and flashing light (75%)

Sensory Sensitivity for Adults

- Music (75%)
- Clothing (75%)
- Public transport sounds (70%)
- Food textures (65%)
- Strong scents (65%)
- Different textures (62%)
- Scent of perfume (60%)
- Hot temperatures (55%)
- **Hypo reactive**
- Physical pain (30%)
- Hot (15%)
- Cold (12%)
- **Sensory seeking**
- Different textures (73%)
- Music (60%)
- Favourite (37%) or spicy food flavours (30%)
- Looking at patterns (35%)

Sensory Sensitivity for Adults

- **Touch** from other people, especially when light or unexpected, different fabric textures and labels in clothing, tight clothing and rough textures
- **Seeking** pressure such as by wearing tight clothing and getting tight hugs from trusted people
- Feeling of warm or cold surfaces on their skin
- **Thematic analysis**
- Impact on mental health, especially anxiety, self-harm and eating disorders

Sensory Sensitivity

- Feel a need to **disengage** (escape) or **shut down**
- Sensory hyperreactivity is often **experienced as physical pain**
- Auditory hyperreactivity impacts sleep
- Seek soothing sensory input as a coping strategy (toolkit)
- Sensitivity moderated by mood
- Physical blocking behaviours (covering eyes, ear or nose)
- Sunglasses and headphones
- If in control of the intensity, the experiences may be more tolerable (music volume)

Meta-synthesis of Sensory Experiences

Sibeoni et al (2022) *Autism* 26, 1032-1045

- Sensory modulation dysfunction model
- Weak Central Coherence
- Enhanced perceptual functioning
- Trigger-Threshold- Target model
- Frontal-posterior underconnectivity
- Intense world theory

Meta-synthesis of Sensory Experiences

- Some report tactile hyposensitivity
- Affects daily activities such as eating and hygiene
- Hygiene included pain or disgust associated with brushing teeth or the smell of soap
- Impeded the ability to pay attention and concentrate
- Associated with anxiety, anger and depression
- Stress can reduce the tolerance of a sensory experience
- Inseparable sensory and emotional experience

Meta-synthesis of Sensory Experiences

- A stressful sensory experience might be judged as agreeable when the participant initiated it
- Concept of control, foresee and avoid
- Sudden or unexpected sensory experiences increased sensory sensitivity
- Avoidance such as removing a disturbing object such as a clock
- Avoid visual contact by closing one's eyes

Meta-synthesis of Sensory Experiences

- Work and school described as noisy, loud and chaotic
- Hospitals and doctor's offices not adapted to an autistic person's sensory sensitivity
- Inability to enter spaces of socialization (bars, libraries etc.)
- Reactive depression to their situations of isolation
- Emotional and sexual relationships problematic due to sensory experiences
- Sensory overload during intimate sexual experiences

Phobias

- **Unusual fears**
- Dickerson-Mayes (2013) *Research in ASD* 7:1
- Unusual fears in over 50% of autistic children
- Fear of mechanical objects (vacuum cleaners, elevators)
- Weather (storms)
- Toilets
- Swings

Sensory Pleasure

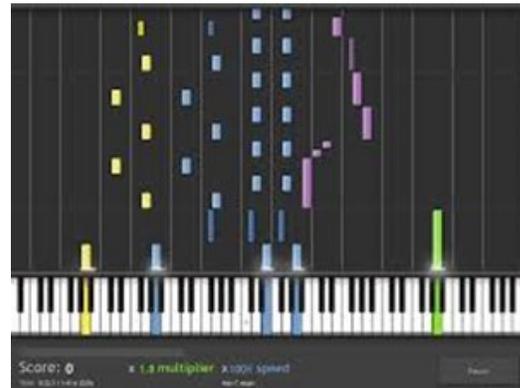
- Smith and Sharp (2013) *Journal of Autism and Developmental Disorders* 43
- Concept of **sensory avalanche** and **sensory fascination**
- Some sensory experiences are extremely pleasurable and relaxing
- Can lead to abilities, such as attention to detail in art due to visual sensitivity



Synaesthesia

- Baron-Cohen et al 2013 *Molecular Autism*
- Sensation on one sensory modality triggers a perception in a second modality
- Autistic adults rate of synaesthesia 18.9%, in controls 7.2%
- Most common grapheme (written word or symbol triggers a colour) or sound-colour
- Aura

SYNESTHESIA
0123456789



Effects on Everyday Life: Classroom

- Howe and Stagg (2016) *Journal of Autism and Developmental Disorders* 46
- Most common was hearing, then touch, smell and vision
- **Affects learning, especially concentration**
- Associated with physical discomfort to pain as well as anxiety
- **Schools need to create sensory profiles** for each autistic student
- *The colours, smells and busyness of my classroom used to give me sensory overload*

Effects on Everyday Life

- *When she was younger, if I had lilies in the house, she'd almost go deaf... it was like the sensory overload made something else shut down*
- **Trauma**
- Characteristics of ASD may determine which events are particularly traumatic such as sensory sensitivity
- **Sleep**
- Noise, light, tactile, temperature
- **Intimacy in a relationship**
- Tactile and olfactory
- **Autistic Burnout**

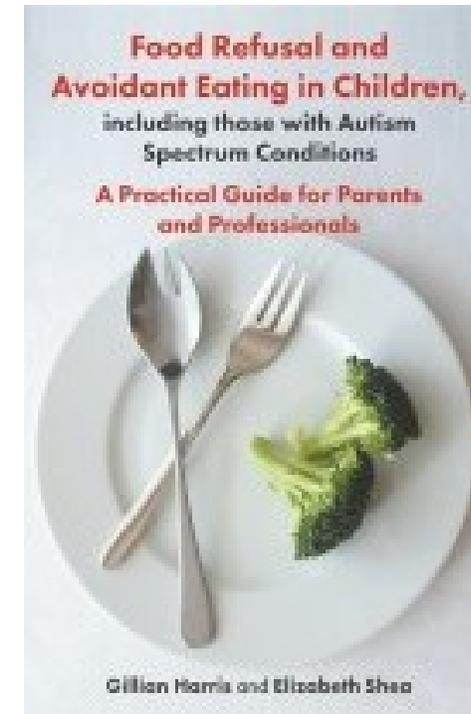
Food

- “I was supersensitive to the texture of food and I had to touch everything with my fingers to see how it felt before I could put it in my mouth. I really hated it when food had things mixed with it....I could never put any of it into my mouth. I knew if I did I would get violently sick”.
- “Eating a pear to me felt like sharp pins being put into my throat”



Eating Disorders: ARFID (Selective Eating Disorder)

- Persistent food restriction where nutritional needs are not met
- Loss of interest in food
- Concern about the consequences of eating (e.g. vomiting)
- Avoidance and anxiety due to the **sensory** characteristics of food



Anorexia Nervosa

Brede et al. (2020) *Journal of Autism and Developmental Disorders* 50, 4280-4296

44 semi-structured interviews, autistic women, parents and healthcare professionals

Thematic Analysis

Sensory overload in life in general and especially the treatment environment

Some women used the effect of starvation on their body to numb these sensations

Food specific sensory sensitivities related to food texture, taste, smell, temperature and mixing different foods limits the range of food tolerance

Motivation for food restriction often related to the sensory properties rather than primarily based on calorie or fat content

Anorexia Nervosa and ASD

- Food sensory sensitivity present since early childhood
- Hypersensitivity to sensory stimuli also applied to internal sensation
- **Interoception**
- Internal sensations associated with eating such as feeling bloated, or the sensation of digesting food were very distressing
- Restricting eating to avoid these sensations

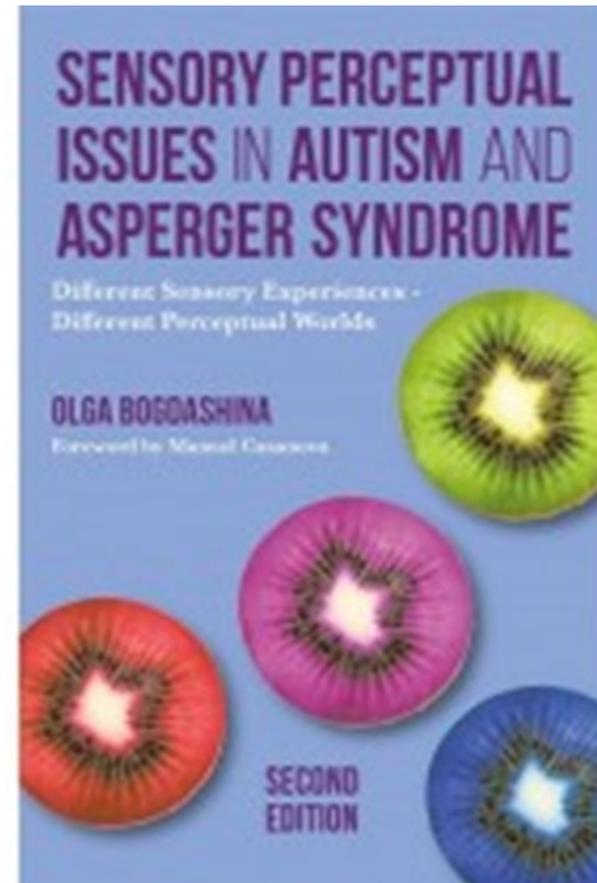
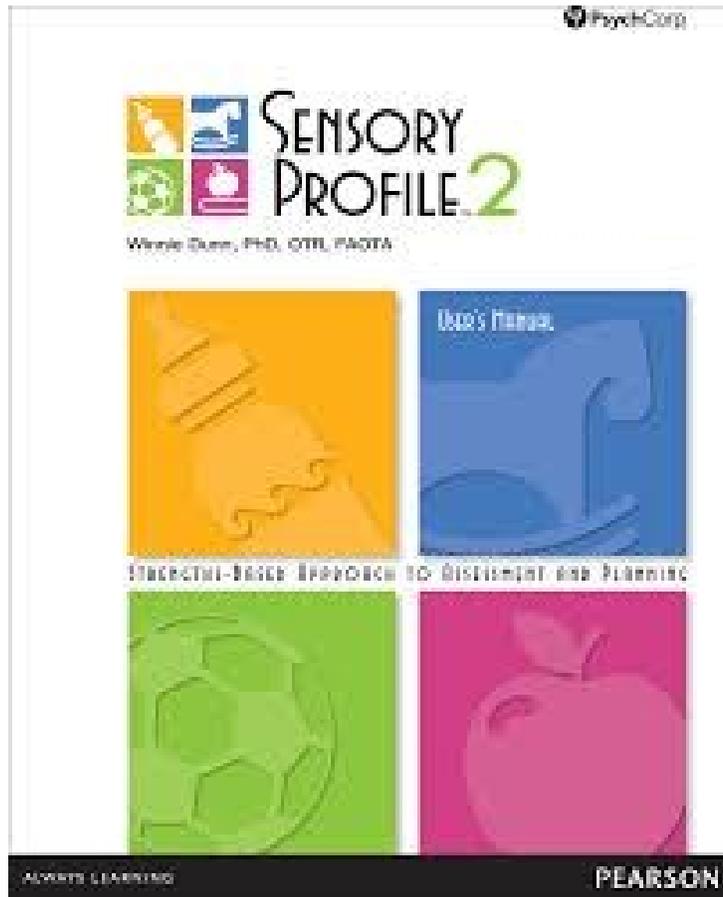
Anorexia Nervosa and ASD

- In contrast, some women talked about hyposensitivity to internal sensations
- Difficulty interpreting feelings of hunger and satiety
- Missing meals because they failed to notice they were hungry
- Not being able to regulate an eating routine without relying on external cues
- *They don't experience hunger in quite the same way*

Menopause and Sensory Sensitivity

- **Parenting**
- Sensory experiences when parenting infants and toddlers (tactile, auditory and olfactory)
- **Menopause and sensory sensitivity**
- Mosely, Druce and Turner-Cobb (2020) *Autism* 24 1423-1437
- Sensory heightening and new sensitivity (especially heat and cold)
- Meltdowns in the context of sensory sensitivity
- *During menopause I was on 3 meltdowns per week*

Assessment Instruments



The Sensory Perception Quotient

- Tavassoli et al 2014 **Molecular Autism 5:29**
- 35 items
- Vision, hearing, touch, smell and taste, such as:
- I can recognize different people by the way they smell
- I can hear electricity humming in the walls
- I can't go out in bright sunlight without sunglasses
- I would be the first to hear if there was a fly in the room

Coping Mechanisms

- **Auditory**
- Identify and avoid the sound if possible.
- Barriers such as earbuds, earplugs or industrial headphones
- Camouflage the perception of the sound with music



Coping Mechanisms

- **Tactile**
- Washing new clothes and removing labels
- Strategies: 'deep pressure'
- Modifying expressions of affection and reassurance
- **Visual**
- Change the intensity and type of illumination.
- Sunglasses.
- Baseball cap, hat or visor.
- Irlen lenses www.Irlen.com

Comfort Kit (Liane Holliday Willey)

- Ear plugs.
- Eucalyptus smelling salts.
- Squishy ball.
- Bendable wire toy.
- Pad of paper and pen to write thoughts.
- Bubble gum.
- Mineral water to cool hot face.
- Favorite book.

Sensory Experiences and Stimming

Charlton et al. (2021) *Research in ASD* 89 101864

- Online survey
- Sensory stimuli caused negative physical sensations – headaches, discomfort and disorientation
- Emotional responses – anxiety and panic, anger and frustrated
- Cognitive effects- confusion and concentrating
- *I can't think or decide what to do*
- *I am unable to comprehend anything going on around me*

Sensory Experiences and Stimming

- *The noise completely consumes me and I cannot focus on anything else*
- Stims a self-regulatory behaviour in response to sensory stimuli
- To regulate emotional and cognitive functioning
- *I think they help me realign the energy in my body better so stuck energy can flow out of me instead of stay in me and cause me pain*
- *Relieve a build-up of feelings before I get overwhelmed*
- *Flapping and singing are when I'm excited, finger flicking when anxious*
- For pleasure and to soothe
- *It can also be just pleasant, I find it comforting and relaxing*

Temple Grandin

- *“Intensely preoccupied with the movement of the spinning coin or lid, I saw nothing or heard nothing. People around me were transparent and no sound intruded on my fixation. It was as if I was deaf. Even a sudden loud noise didn’t startle me from my world. But when I was in the world of people, I was extremely sensitive to noise”*



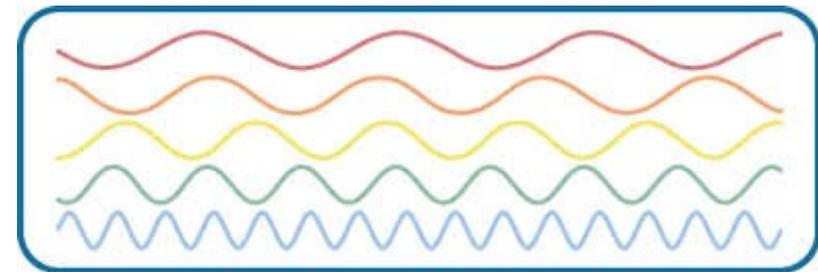
Emotional Empathy



- Overly sensitive to another person's negative mood
- Hyper-sensitive to disappointment, anxiety or agitation
- *There's a kind of instant subconscious reaction to the emotional states of other people that I have understood better in myself over the years*
- *If someone approaches me for a conversation and they are full of worry, fear or anger, I find myself suddenly in the same state of emotion*
- *Emotions are contagious for me*

Emotional Empathy

- *I am able to distinguish very subtle cues that others would not see, or it might be a feeling I pick up from them*
- A 'sixth sense'
- Avoidance of some social situations due to being sensitive to 'negative vibes'



Emotional Empathy

- Sensitivity to a teacher's or peer's mood
- Not wanting to upset the teacher by reporting difficulties
- Being 'infected' by someone's mood
- Reason for social withdrawal
- Trying to create harmony between friends when they have disagreements- want everyone to be happy

Interoception

- Sensing the **internal** world
- Pain, illness (vomiting)
- Heart rate and breathing
- Hunger
- Temperature
- Emotions – ‘ick’



Interoception

- A mind/body division
- *“Autism is being locked inside yourself, but it’s being disconnected from yourself too”*
- Diagnostic assessment of an adult
- “How did you know.....?”
- “I only know what I am feeling by seeing what I am doing”

The Interoception Sensory Questionnaire

ISQ-8

- Suzman et al (2021) Molecular Autism 12:42
- **ISQ-8** has eight items with five response choices from not true at all to very true of me
- 495 autistic adults and 187 autistic adolescents

8 Items

1: I have difficulty making sense of my body's signals unless they are very strong

2: I have difficulty feeling my bodily need for food

3: I'm not sure how my body feels when it's a hot day

The Interoception Sensory Questionnaire

ISQ-8

4: I find it difficult to describe feelings like hunger, thirst, hot or cold

5: There are times when I am only aware of changes in my body because of the reactions of other people

6: I find it difficult to identify some of the signals that my body is telling me (e.g. If I'm about to faint or I've overexerted myself)

7: I have difficulty locating injury on my body

8: Even when I know that I am physically uncomfortable, I do not act to change my situation

Interoception

- Trevisan, Parker and McPartland (2021) *Journal of Autism and Developmental Disorders* 51, 3483-3491
- Analyzed 597 posts from discussion forums on www.wrongplanet.net
- **Limited awareness of hunger, satiation and thirst**
- Forgetting to eat or drink for long periods of time
- Difficulty ascertaining when they had enough to eat
- *I don't feel satiated until I'm really, really full*
- **Limited awareness of pain, injury, illness or exhaustion**
- *I had no idea I was sick, or going to vomit until about 3 seconds before I did so*
- **Incontinence**
- *I'm insensitive to my body's signal that I need to go...I'm very often extremely desperate to go once I finally realise...*

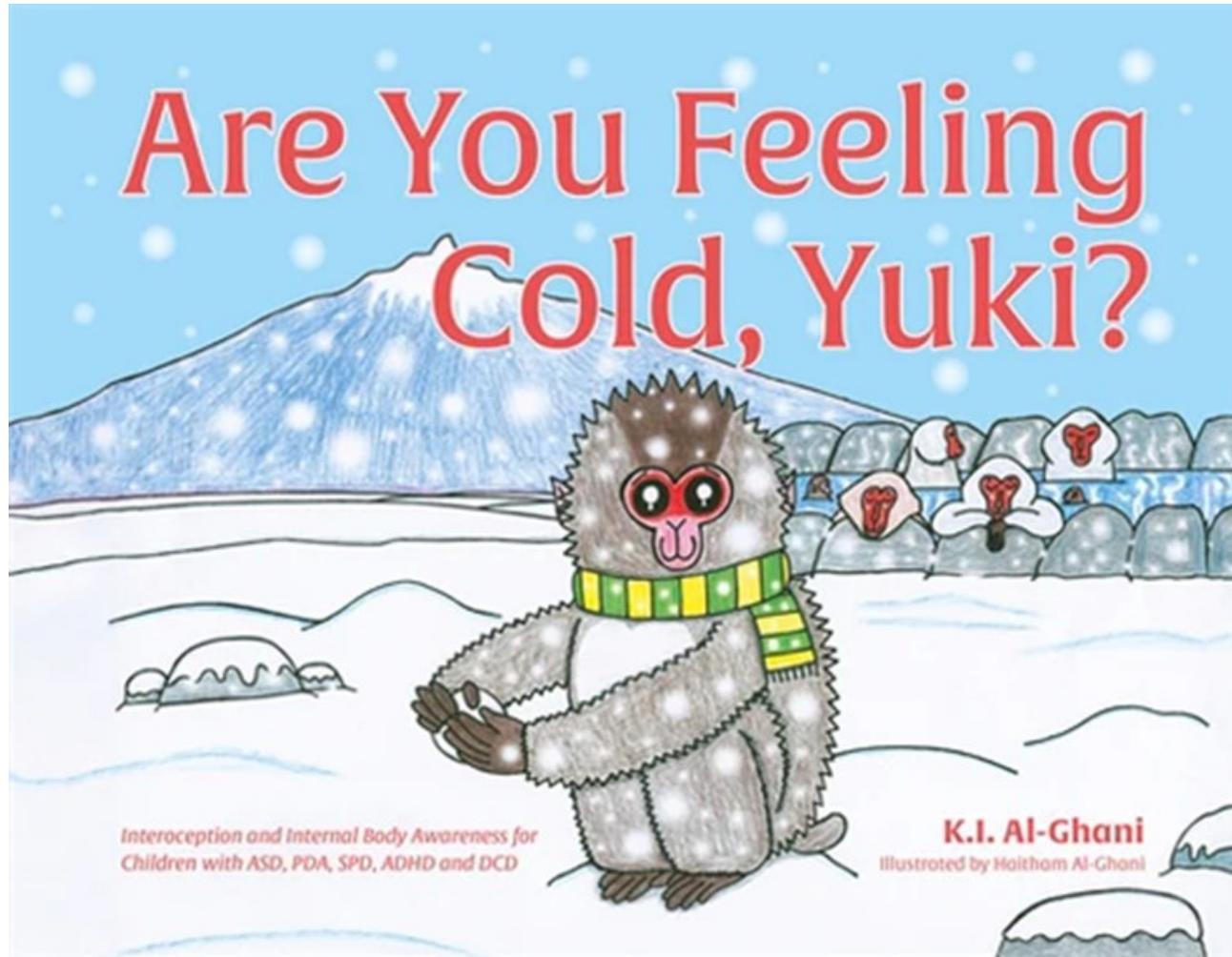
Interoception

- **Hyper-sensibility/hypochondria**
- *Over-sensitivity to, or worry about, internal body signals*
- *I'm super sensitive to any little changes in how my body feels and I always worry that I might have some serious deadly terminal scary disease*
- *When I'm really sad, it physically hurts. The best way I can describe it as it's like my whole-body stings very very badly or is on fire*

Interoception

- **Poor interoceptive accuracy/confusion**
- Can detect interoceptive cues but fail to accurately interpret them
- *At the moment there is “a sensation” in my stomach. This poses a problem. Because I can’t understand what it is.*
- *The best way I can describe this to health professionals is that I receive a signal from somewhere I’m not exactly sure, and I have difficulties interpreting what they might mean*
- **Interoceptive dysfunction may play a role in alexithymia and perceiving emotional arousal**

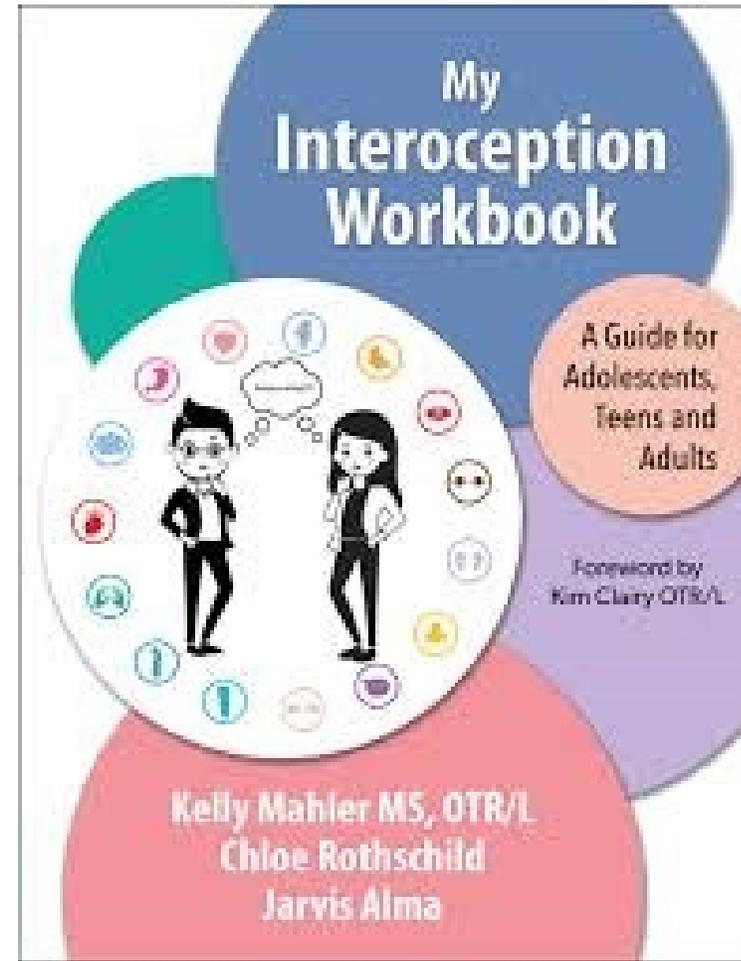
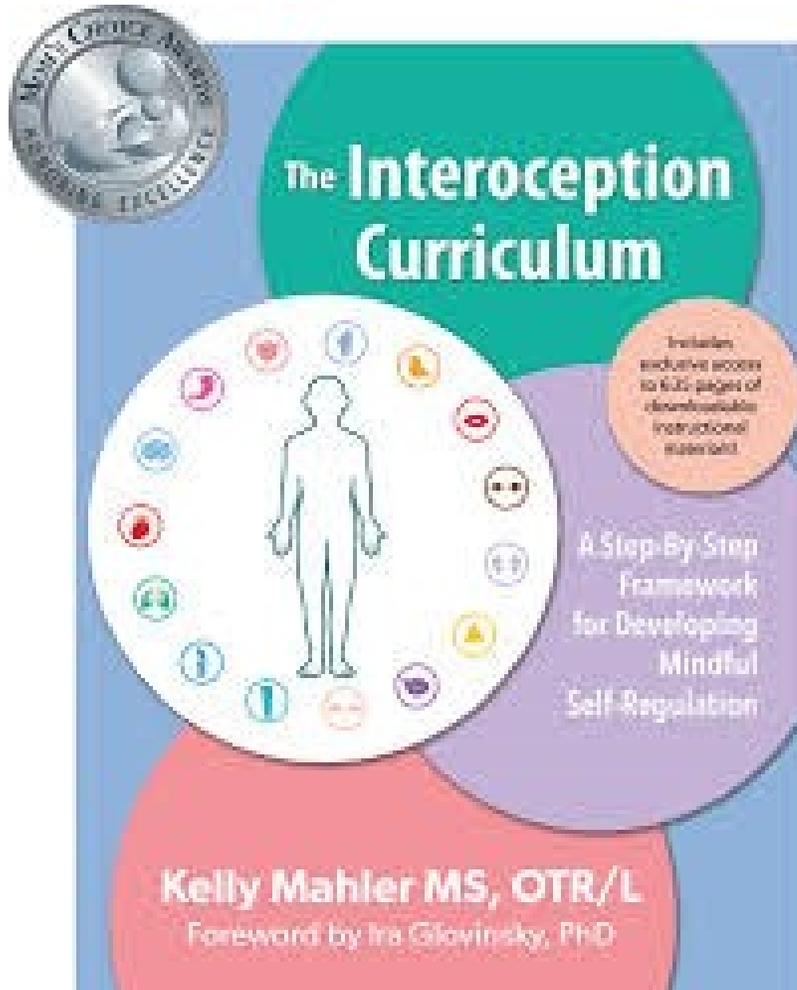
Are You Feeling Cold, Yuki?



*Interoception and Internal Body Awareness for
Children with ASD, PDA, SPD, ADHD and DCD*

K.I. Al-Ghani
Illustrated by Haltham Al-Ghani

The Interoception Curriculum



Strategies for accommodating difficulties with interoception

Sports watch technology to measure heart rate

- Signs of increasing agitation
- Signs of increasing relaxation
- Heart rate throughout the day



Strategies for accommodating difficulties with interoception

- Autism assistance dog

