OCD and Anxiety Disorders in Individuals with Down Syndrome

Risk Factors, Interventions and Family Supports

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Objectives

- Learn why individuals with Down Syndrome are at increased risk for Obsessive-Compulsive Disorder (OCD) and other Anxiety Disorders throughout development.
- Understand ways in which cognitive-behavioral treatments (CBT) can be effective for individuals to use on their own and with support by family members and care providers.
Outline

- Well-being and *good* mental health
- Understanding Anxiety Disorders and OCD
  - Diagnostic criteria
- Next steps
  - Prevention, assessment and treatment options
- Discussion and questions
WELL-BEING AND GOOD MENTAL HEALTH
What is Mental Health?

- Mental health conditions/problems vs. “good mental health”

- World Health Organization (WHO):
  - “a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully and is able to make a contribution to his or her community.”
Mental Health and Down Syndrome (DS)

- In the past, mental health conditions in people with DS were often disregarded as part of the “diagnosis”

- Currently, about 50% of children and adults with DS experience some mental health concern in their lifetime and additional vulnerabilities are known

Reference: National Down Syndrome Society
Well-Being and Mental Health Development

- **Normal vs. Abnormal Behavior**
  - Importance of knowing usual vs. unusual behaviour on a continuum

- **Additional Considerations**
  - Developmental age and cognitive capacities
  - Language skills and delays
  - Environmental stressors and experiences

Reference: Mental Wellness in Adults with Down Syndrome
Mental Health (Problems)

Internalizing Disorders  
“Over Control”
- Anxiety
- Depression
- Social Withdrawal

Externalizing Disorders  
“Under Control”
- ADHD
- Conduct Disorders
- Delinquent Behaviour
Vulnerabilities for Poor Mental Health

- Multiple medical problems lead to higher rates of mental health problems
- Most common mental health concerns include:
  - General anxiety, repetitive and obsessive-compulsive behaviors
  - Oppositional, impulsive, and inattentive behaviors
  - Sleep related difficulties
  - Depression
  - Autism spectrum conditions
  - Neuropsychological problems characterized by progressive loss of cognitive skills

Reference: National Down Syndrome Society
Vulnerabilities for Poor Mental Health

- Differences in language and communication, cognition leads to different risks for:
  - Young and early school-aged children
    - E.g., Disruptive and impulsive disorders
  - Older school-aged children, adolescents and young adults
    - E.g., Depression, generalized anxiety disorder
  - Older adults
    - E.g., Generalized anxiety disorder, social withdrawal

Reference: National Down Syndrome Society
ANXIETY DISORDERS AND OCD (DIAGNOSIS AND CRITERIA)
Anxiety and Obsessive Compulsive Disorders

- What is anxiety, fear and phobias?
  - What are the common features?
- What is an Anxiety Disorder?
  - How do you identify or diagnosis an Anxiety Disorder?
- What is a compulsion or obsession?
  - How do you identify a Obsessive-Compulsive Disorder?
Anxiety Features

What is Anxiety?

- 3 components
  - Physical
  - Mental
  - Behavioural

- Purpose of Anxiety = Protection
  - E.g., Walking through a dark alleyway

- Flight, Fight, Freeze
Anxiety Features: Three Components of Anxiety

Event: Internal/External

Feelings

Thoughts

Behaviours
Anxiety Features

- **Fear**
  - Response to real, immediate danger

- **Anxiety**
  - Different from fear
  - Low levels can be adaptive

- **Maladaptive Anxiety**
  - High levels of diffuse negative emotion
  - Sense of uncontrollability
  - Shift in attention to state of self-preoccupation

- **Neuroses**
  - Unrealistic anxiety and associated problems
Anxiety Disorders: Overview

- Anxiety is a protective mechanism, but becomes a **disorder** when ongoing and interfering with day-to-day functioning

- **SP = Specific Phobia**
  - Fear of “something”

- **GAD = Generalized Anxiety Disorder**
  - Fear of “everything,” worries

- **Panic Disorder = Panic Disorder**
  - Fear of anxious symptoms

- **Agoraphobia**
  - Fear of being in certain places
Specific Phobia: Criteria

- Such fears are quite common among very young children, are generally not debilitating, and tend to disappear as the child grows older
- Exposure to the phobic stimulus almost invariably provokes an immediate anxiety response
  - E.g., Panic Attack or panic-like symptoms
Specific Phobia: Subtypes

- **Animal Type**
  - Animals, insects
- **Natural Environment Type**
  - Heights, storms, water
- **Blood-Injection-Injury Type**
  - Blood, needles, injuries
- **Situational Type**
  - Public transportation, elevators, tunnels
- **Other Type**
  - Open spaces?
Generalized Anxiety Disorder: Criteria

- Characterized by excessive or unrealistic anxiety or worry over a number of issues including family matters, friendships, future activities, past performance, keeping schedules or routines, and health of self and others
- Difficult to control the worry
- Associated with “1” (or more) of:
  - restlessness or feeling keyed up or on edge
  - being easily fatigued
  - difficulty concentrating or mind going blank
  - irritability
  - muscle tension
  - sleep disturbance
Panic Disorder: Criteria

- Anxiety without obvious threat
  - E.g., Due to “stress”

- We need an explanation
  - Search inward

- “Something must be wrong with me”
Panic Attacks: Criteria

**Panic Attack**
- Sudden fear or discomfort
- Peaks within 10 min.

**4 or more of following:**
- Chest pain or other chest discomfort
- Chills or hot flashes
- Choking sensation
- Derealization
- Depersonalization
- Dizzy, lightheaded, faint or unsteady
- Fear of dying, loss of control or becoming insane
- Heart pounds, races or skips beats
- Nausea or other abdominal discomfort
- Numbness or tingling
- Sweating
- Shortness of breath or smothering sensation
- Trembling
Panic Disorder: Criteria

- **Panic Disorder**
  - Recurrent panic attacks that are not expected
  - For a month or more after at least 1 of these attacks, the person has had 1 or more of:
    - Ongoing concern of more attacks
    - Worry about significance/consequences
    - Significant change in behavior

- Panic Disorder with Agoraphobia
- Panic Disorder without Agoraphobia
Agoraphobia

- Fear of being in certain places or situations, typically because of some previous negative experience associated with the situation/place.
- Often includes refusal to leave home due to fear or worry about going to feared situation/place.
Obsessive-Compulsive Disorder (OCD)

- What are repetitive behaviours and thoughts?
- What is OCD?
- How is OCD diagnosed?
Obsessive-Compulsive Disorder (OCD)

- People with Down Syndrome and tendency for repetition and sameness
  - Beneficial (e.g., self-care, routines)
  - Problematic (e.g., stuck with thoughts, rigidity)
- Diagnosis of OCD may or may not be related to the “grooves”
- 1.5-2.3 % of population; ~6% of People with DS
Obsessive-Compulsive Disorder (OCD)

- What are repetitive behaviours and thoughts?
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OCD: Obsessions

- Recurrent/persistent thoughts, images, or impulses that are intrusive, inappropriate, and cause anxiety/distress
- Not simply excessive worries about real life problems
- Person attempts to ignore/suppress/neutralize them
- Person recognizes them as their own
OCD: Compulsions

- Repetitive behaviours or mental acts performed in response to an obsession or according to rigid rules
- Aimed at reducing distress or preventing a dreaded event
- Not connected in any realistic way with what they are designed to prevent
- Objectively excessive
OCD: Criteria

- **General criteria:**
  - Presence of obsessions and compulsions
  - Significantly impact your daily life
  - You may or may not realize that your obsessions and compulsions are excessive or unreasonable

- **Obsessions must meet specific criteria, including:**
  - You may or may not know that your mind simply generates these thoughts and that they do not pose a true threat

- **Compulsions must meet specific criteria, including**
  - Take up at least one hour or more per day

NEXT STEPS
Next Steps

- Prevention
- Assessment
- Treatment
PREVENTION
Prevention

- **Tips for Good Mental Health**
- **Factors that contribute to good mental health are the same for people with or without DS, include:**
  - Feeling good about one’s self = Self-Esteem
  - Understanding self
  - Positive role models
  - Supports and family structure
  - Control (lack of helplessness)
  - Opportunities
Prevention

- **Healthy Self-Esteem**
  - Accepting who you are as a person
  - Most youth at any point, struggle with self-esteem (with or without DS)

- **Tips for developing Healthy Self-esteem**
  - Identity – simple and concrete, focus on talents and strengths and personality.
  - Support person to take as much control over their own life as possible.
  - Encourage friendships, independence and social interaction with people their own age.

Reference: Mental Wellness in Adults with Down Syndrome
ASSESSMENT
Assessment

- In general, continued improvement of mental health concerns for children and adults
  - Diagnostic screening tools, structured assessment protocols
- Improvement in ability to assess given differences in developmental age groups, in terms of measurement of domains such as:
  - Non-verbal problem-solving abilities, language and communication and adaptive and behavioral functioning.

Reference: National Down Syndrome Society
Assessment

- How do you distinguish medical conditions from Anxiety Disorders?
- Rule-outs? Some examples, include:
  - Thyroid function
  - Sleep related difficulties
  - Underlying contribution of constipation or bowel related difficulties
- Caveats to treating potential “medical concerns”

Reference: National Down Syndrome Society
Assessment

- Potential providers with experience in working with children and adults with developmental disorders
  - Ideal mental health provider (i.e., behavioural therapy)
  - Ideal psychiatric provider (i.e., medication)
- Balance between diagnostic criteria and knowledge of the individual’s typical behaviour and level of interference in daily life
- Multiple sources of information
  - Tracking information, recording logs of behaviour etc.

Reference: National Down Syndrome Society
TREATMENT
Cognitive Behavioural Therapy (CBT) Fundamentals

- Individualized
- Time-Limited
- Educational
- Self-Directed
- Skills Training
- Contracting
- Goal Setting

- Recognizing and Controlling Cues
- Self-Talk
- Graded Exposure
- Monitored
- Evaluated
- Family involvement
Treatment

- **Counselling and Psychoeducation**
  - Goal to express concerns and ideas
  - Understand the ABCs
    - Antecedents, behaviours and consequences
  - Involve other care providers or support workers
Specific Phobia: Treatment

- Effectively treated with Behaviour Therapy
- Exposure treatment
  - Counter-conditioning: relaxation + exposure
    - Systematic desensitization
  - Anxiety Hierarchy
  - Modeling: Social learning theory
  - Rewards (natural and specific)
Generalized Anxiety Disorder: Treatment

- Acknowledging worry as bothersome or worth addressing
- Challenging worries (when possible)
  - Coping Cards
- Attention to heightened worry (or triggers) to allow for:
  - Increased awareness and “prevention”
  - Dedicated relaxation strategies and time
Generalized Anxiety Disorder: Treatment

- **Relaxation Exercises**
  - Progressive Muscle Relaxation (PMR)
  - Belly Breathing (Diaphragmatic Breathing)
    - Practice, Practice, Practice!
  - Visualization (Imagery)

Panic Disorder + Agoraphobia: Treatment

- Time, patience and “detective work” to understand situations (or locations) that cause fear in individual
  - May or may not be based on a previous experience (i.e., re-experienced trauma?)
- Risk of facing feared-situation can be reduced (when suitable or identified) or focus on desensitization
Panic Disorder and Agoraphobia: Treatment

- **Desensitization**
  - Gradual exposure to feared situation to reduce fear by increasing tolerance

Reference: www.simplypsychology.org/Systematic-Desensitisation
Panic Disorder and Agoraphobia: Treatment

- **Desensitization**
  - Replace SPIDER with RIDES IN CAR
  - Daily process, repetition, lots of interim steps

OCD: Treatment

- CBT Educational Phase
- Exposure and Response Prevention
- Exposure
  - Expose the patient to the feared situation or situation that triggers the obsession or urge to ritualize (e.g. dirt, germs)
- Response Prevention
  - Prevent the patient from engaging in ritual behaviour (e.g. washing, cleaning)
OCD: Treatment

- Understanding possible causes or precipitants (e.g., triggers, people in environment)
- Redirection (before or just after onset of a compulsion or obsession)
  - Gradually introducing a predetermined alternative activity that is rewarded
  - 1 change focus at a time

OCD: Treatment

- Compulsions
  - Ordering of objects
    - Healthy “groove”?
  - Hoarding of items
    - Redirection can be challenging; focus on safety and limit setting
  - Excessive rigidity for routines
    - Incentives for alternatives until new routines are formed

- Forming alternative ways to experience control in one’s environment and life

OCD: Treatment

- **Obsessions**
  - Real “people” or imagined “people” or celebrity
    - May not understand underlying reason

- **Redirecting attention**
  - E.g., written vs. verbal form

- **Appropriate medication assessment/trial**

Treatment: Practical Tips

- Focus on the positives
  - Can do vs. can’t do
- Foster strengths and talents
- Opportunities to express feelings
- Support healthy lifestyle
  - i.e., exercise, diet
- Support independence and decision-making
- Remember Change is a Process

Reference: Down's Syndrome Association (UK)
Discussion and Questions

- Do you have a better understanding of how anxiety and compulsive behaviours are identified and/or diagnosed?
- Do you have a better understanding of the prevention, assessment or treatment for people with developmental disabilities?
- Questions?
References and Resources

- National Down Syndrome Society
  - http://www.ndss.org/
- Feeling Down: Looking After My Mental Health
- Down's Syndrome Association (UK)
  - https://www.downs-syndrome.org.uk/
- AnxietyBC
  - https://www.anxietybc.com/self-help