Challenging Behaviours in Persons with Intellectual Disability: The Whole Person Approach

Tutorial & Panel Discussion

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Outline for Tutorial

• Introduction to Primary Care Guidelines
• VC sites and panelists discuss each of 3 case studies, with corresponding questions
• General questions for panelists
• Site feedback for future such sessions

Primary Care of Adults with Dev Dis:
Canadian Consensus Guidelines (2011)

• Describe best practices in caring for adults with DD
• Reviewed and published in Canadian Family Physician journal - May 2011; Vol 57(5), 541-553
• Available online at: http://www.cfp.ca/content/57/5/541.full.pdf
• Considerations:
  o General issues (9)
  o Physical health issues (12)
  o Behavioural and mental health issues (10)
Tools for the Primary Care of People with DD

- Developed to assist Primary Care Providers in "how-to" of applying Guidelines
- Electronic versions of Tools available at: http://www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx
- Also some tools developed for caregivers (group home staff, family members) and people with DD

Case Study 1: Owen (Age - 18)

- Mild to moderate intellectual disability
- Adopted in infancy; lives with parents and 14-year-old sister who is a biological child of parents
- He has always been restless/hyper, and has had difficulty with unexpected changes and transitions
- As a child other kids called him "Dumbo" because of his prominent ears
- Owen has become increasingly angry and sometimes aggressive over past 6 months
  - Punched holes in wall, broken objects, pushed mother & sister
- Still in school but refuses to attend 50% of days
  - School also reporting increased anger & aggression

Owen – Age 18

- Mother says that she and Owen had always been close
- He has never done much outside the home because he was nervous about new things and meeting people; his mother preferred not to stress him
- Mother returned to the work force a year ago following death of her mother
- Father works long hours and mother admits they are not getting along
- Owen’s sister presents with no problems – does well in school and is a competitive gymnast, now frequently attends meets on weekends
Owen – Age 18

- When at home:
  - He spends most of time withdrawn to his room
  - Very hard to rouse in mornings and tired most days
  - He has become a voracious eater & has gained 20 lbs
  - No longer seems interested in playing video games

- Both at home and at school:
  - Often seems to tune out and seems unresponsive for short periods

- Seen by family physician 3 months ago and started on risperidone, but this has not helped

Questions to Consider:

1. Keeping in mind the importance of a biopsychosocial model, what possible factors might be contributing to Owen’s problems?

2. What steps would you take to explore these possibilities further?

3. What additional resources might be considered?

Relevant Primary Care Guidelines

- **Guideline 2**: Etiology of DD is useful to establish as it often informs preventive care or treatment

- **Guideline 6**: Abuse / neglect of adults with DD occur frequently

- **Guideline 10**: Physical inactivity & obesity are prevalent in adults with DD; health promotion can improve attitudes toward physical activity & life satisfaction

- **Guideline 18**: Epilepsy is prevalent in adults with DD

- **Guideline 22**: Problem behaviour is not a psychiatric disorder but might be a symptom of a health-related disorder or other environmental / emotional factors
Relevant Primary Care Guidelines (cont’d)

- Guideline 23: Psychiatric disorders are more common in adults with DD but might not be recognized or addressed appropriately.
- Guideline 25: Input from adults with DD and caregivers are vital for understanding of problem behaviours and implementing interventions.
- Guideline 26: Interventions other than medication are usually effective for alleviating problem behaviour.
- Guideline 27: Psychiatric medications are effective for robust psychiatric diagnoses.
- Guideline 28: Antipsychotic medications are often inappropriately prescribed for adults with DD and behavioural problems.

Tools for Primary Care of People with DD

- Genetic Assessment: FAQ
- Health Watch Table for Fragile X
- Communicating Effectively with People with DD
- Today’s Visit
- Cumulative Patient Profile
- A Guide to Understanding Behavioural Problems & Emotional Concerns

Case Study 2: Evelyn (Age - 47)

- Has Down syndrome
- Known medical issues causing dysphagia leads to choking and nutritional issues.
- Osteoporosis diagnosed 3 years prior
- Significant dental issues, most teeth pulled out 2 years ago under anesthesia, last dental exam was also done during this time.
- Long history of physically aggressive and self-injurious behaviors
- Has been living in the home for several years; however, she has a new room mate whom she seems to get along with.
Evelyn – Age 47

• Limited verbal language; however, she understands day-to-day instructions.

• The medications she has taken for many years includes:
  o Levothyroxin 12.5 mg/day (Throid)
  o Alendronate 10 mg/day (osteoporosis)
  o Seroquel 50 mg/day (psychotropic)
  o Calcium 1000mg/day
  o Vitamin D 600mg/day
  o Dilantin 125 mg/day (anticonvulsant)
  o Trazadone 25 mg QHS PRN (Help with sleep)

Evelyn – Age 47

• She was doing well until December of 2011 when her behaviour started deteriorating.
  o Increased aggressiveness and self-injurious behaviour
  o Makes grunting/puffing sounds
  o Decrease in sleep at night
  o Decrease in appetite

Questions to Consider:

• What would be the first steps to take?

• What are some tools that could be used to assist?
Relevant Primary Care Guidelines

• Guideline 4: Pain and distress, often go unrecognized, might present atypically in people with DD.
• Guideline 5: Multiple or long-term use of some medications can cause harm that is preventable.
• Guideline 12: Dental disease is among the most common health problems in adults with DD.
• Guideline 15: Gastrointestinal and feeding problems are common among adults with DD.
• Guideline 18: Epilepsy is prevalent among adults with DD and increases with the severity of the DD.

Relevant Primary Care Guidelines (cont’d)

• Guideline 22: Problem behaviour, such as aggression and self-injury, is not a psychiatric disorder but might be a symptom of a health related disorder or other circumstance.
• Guideline 27: Psychotropic medications can be problematic for adults with DD and should therefore be used judiciously.
• Guideline 28: Antipsychotic medications are often inappropriately prescribed for adults with behaviour problems with DD.

Suggestions

• Staff at home should be using assessment tools such as:
  – Today’s visit (tool kit)
  – Stool Chart
  – Sleep chart
  – Down Syndrome Health watch table (physician tool)
  – Caregiver assessment tool
• An appointment should be made with Family physician
  – Alendronate has a side effect of causing GERD which could explain the symptoms listed above. If person started on a proton pump eliminator med such as prevacid, it could resolve issues.
• An appointment should be made with dentist
Case Study 3: David (Age – 37)

- David is a 37-year-old man with Down Syndrome and a diagnosis of Bipolar Disorder.
- David’s mood has been stable for two years with his current regime of Lithium.
- He is an active man in the summer who plays baseball and is on the swim team with Special Olympics.
- He has struggled with weight due to winter inactivity and side effects to medications.
- This summer he moved into a shared residence arrangement with 2 other men after a difficult winter in his own apartment.

David – Age 37

- Usually keeps to himself in the home and prefers own space.
- Had been taking pain medication for an ongoing dental issue.
- Had been enjoying activities and there were no concerns in the home as he settled in.
- This November he began refusing meals and becoming aggressive towards one particular housemate.
- This was shortly after a dental surgery to have two teeth reconstructed that had been problematic for some time.
- David also began eloping from the residence a few times per week around this time.

- Pain medication and antibiotics had been prescribed following the dental surgery and no concerns were noted.
- Aggressive behaviour continued to escalate for three more months and then returned to baseline over the following two months.
David – Age 37

Questions to Consider:

• From a biopsychosocial perspective, what factors might be at work here?
• What are some possible next steps that could be taken?
• Are there resources we should consider in this situation?

Relevant Primary Care Guidelines

• Guideline 4: Pain and distress – Often unrecognized and could be indicted by changes in behaviour.
• Guideline 10: Physical inactivity and obesity – Associated with a number of adverse health outcomes.
• Guideline 12: Dental disease – Most common health problem for adults with DD.
• Guideline 22: Problem behaviour – Not necessarily the result of a psychiatric disorder and could be health or environmentally related.

Relevant Primary Care Guidelines (cont’d)

• Guideline 23: Psychiatric disorders – Can be under recognized in people with DD due to diagnostic overshadowing.
• Guideline 26: Interventions other than medication – Can include sensory and environmental assessment, behavioural interventions, and skill development.
• Guideline 27: Psychotropic medications – Should be used judiciously since specific psychiatric diagnosis may not always be possible.
Tools for Primary Care of People with DD

- Communicating Effectively with People with Developmental Disabilities
- Preventative Care Checklist Form – Adult Males with DD
- Health Watch Tables – Down Syndrome
- A Guide to Understanding Behavioural Problems and Emotional Concerns
- ABC (Antecedent, Behaviour, Consequence) Chart
- Auditing Psychotropic Medication Therapy