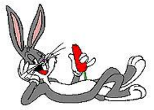
What's Up, Doc?



Terry Broda
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Pain?

- How to assess pain?
- How to recognize if a person is in pain/distress?
- Difficulty in pain assessment can be fatal!

(death d/t intestinal obstruction is 34 X more common in persons with I/DD)

Pain?

SOLUTION-S

Usual inferences of pain include information from:

- language (content: expressive & receptive);
- qualities of speech: tone, dynamics;
- non-verbal vocalizations: crying, moaning;
- non-vocal behaviour: facial expressions, bodily movements (guarding, limping);
- physiological indicators: respirations, pallor, flushing, sweating, muscle tension.

(Melzack, p.136)

Pain?

Which is it?…..

Pain insensitivity vs tactile sensitivity?

Pain insensitivity vs non-reporting/denial?

Pain insensitivity vs receptive language problem?

Pain?

Methods:

- self-report;
- observation;
- proxy reports;
- physiological reactions.

Self-Report

SOLUTION·S

Scales:

- 1-10;
- faces (Wong, Oucher);
- thermometer;
- mild/moderate/severe;
- compare to actual life events: have you ever fallen & broken a bone? Been stung by a bee? Gotten an injection?

Observation Scales

SOLUTION·S

- CHEOPS (Children's Hospital of Eastern Ontario Pain Scale)*
- Gedye Discomfort scale*
- FACS: Facial Action Coding System (slow-motion video of facial movements)
- *BUT are dependant on observers' backgrounds, or prior experience w/ pain

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Proxy Reports

SOLUTION·S

- Non-communicating Children's Checklist by McGrath & Breau

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Physiological Reactions

- Distress vs pain, difficult to determine physiologically (increased pulse & respirations may occur before & during painful event).
- Pain imaging studies are promising.

Individualized Procedures

- Individual manifestations.
- Individual impairments: physical & cognitive.

Therefore we need:

- individual behaviour checklists (using pt's repertoire of pain behaviours);
- individual global rating scale (0-5 rating by parents or caregivers, for each pain level).

Individualized Behaviours

- CB vs avoidance/reduction in activity.
- KNOW YOUR PATIENT/CLIENT!
- OVERESTIMATION OF RECEPTIVE COMMUNICATION CAN BE PROBLEMATIC!

  (Studies have shown that staff overestimate comprehension abilities & underestimate hearing difficulties & overuse verbal instruction especially w/ pts w/ profound DI!)
- KNOW THE CONTEXT!
- Distress may be hidden but is never silent!

Some Statistics…

SOlUTION·S

- (1995) Study of 224 adults found a strong association between physical health & depression (specifically pain & subjective health);
- (1992) Meta-analysis of 9000 adults presenting with psychiatric complaints:
  - 42.4% had unrecognized medical complaints;
  - 17% contributed directly to the psychiatric condition.

Depression or ???

SOlUTION·S

- Symptoms:

  behaviour such as withdrawal, sleep disturbance, decreased appetite, changes in activity level, changes in sexual performance, & self-injurious or suicidal behaviour, but can also include aggression, agitation, & stereotypic behaviour

but …..

Depression has been linked to:

SOlUTION·S

- overactive bladder;
- COPD;
- Parkinson's;
- # d/t osteoporosis;
- end-stage renal disease;
- malignancies;
- folate deficiency;
- chronic pain;
- sleep apnea;
- infections;
- arthritis;
- diabetic neuropathy;
- celiac disease;
- gynecological disorders;
- thyroid disorder;

Changes in Appetite & Weight:

SOLUTION·S

- diabetes;
- hyperthyroidism;
- hypothyroidism;
- hypoparathyroidism;
- malignancies/tumours/cancer;
- problems related to intake, retention, absorption, or metabolism.

Agitation

SOLUTION·S

- Endocrine disorders:
  - Thyroid
  - Hypoglycemia
- Neurological disorders:
  - Increased intracranial pressure (ICP)
  - Epilepsy
- Side effects of Rx

Intensive Evaluation Needed:

SOLUTION·S

- observation & data collection;
- taking a thorough history;
- review of systems;
- physical exam;
- investigations;

Exercise #1

SOLUTION-S

a) Mr. Brown lives in a foster home with two other clients. To accommodate a new client who moved in last week, he now shares a room with Mr. White. For the last two days Mr. Brown's bed has been wet in the morning & Mr. Brown's pyjamas indicate he has urinary incontinence. When staff try to help him change his clothes, Mr. Brown hits them. He is unable to dress himself & usually requires staff assistance. Mr. Brown is diagnosed with Down Syndrome & moderate mental retardation. He has a limited vocabulary & often communicates with simple gestures.

Exercise #1

SOLUTION-S

- What are your hypotheses for his behaviour & what are pertinent questions to ask at this time for further clarification?

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Exercise #1

SOLUTION-S

-

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Exercise #1

SOLUTION·S

- Mr. Brown is 53 years old. He has never been incontinent before except for 3 years ago when he had a urinary tract infection (UTI). What else would you ask about now?
- What information is most important to convey to the doctor?

Exercise #1

SOLUTION·S

-

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Pain

SOLUTION·S

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Pain

SOLUTION·S

Acute Pain:

- migraine, otitis, conjunctivitis, bronchitis, sinusitis, laryngitis, dental pain, shingles;
- menstruation, urinary tract infection, vaginitis, prostatitis;
- constipation, reflux, diarrhea, allergies;
- fractures, sprains, acute injuries.

Chronic Pain:

- arthritis;
- neuropathies.

To Consider… (Ryan, 2001)

SOLUTION·S

- Challenging behaviour (CB) may indicate a health problem (physical or mental).
- These same CBs may mean different things at different times.
- EVERY CB means something!
- Pain that you can control is preferable to pain that is out of control!
- Often, our clients have learned NOT to complain.

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Co-morbidities

SOLUTION·S

- **Have higher rates** of some health problems
  [e.g.: seizures (25x); GERD; constipation; sensory impairments; obesity, behavioural and mental health problems]
- **Have earlier onset** (e.g. osteoporosis, dementia)
- **Have different symptoms** (e.g. dysphagia)
- **Have complicating factors** (e.g. multiple and long-term medications)
- **Have vulnerabilities** (e.g. abuse, infections, people with ASD – vulnerability to sensory stimuli)
- May have **musculoskeletal and motor problems** affecting office access; use of equipment.

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Signs to observe…

SOLUTION·S

- What part of the body is touched?
- What part of the body is tense/rigid?
- What part of the body is protected?
- What movement is avoided?
- Refusals (to dress, to eat,…)

Useful Tools

SOLUTION·S

- Scatter plots
- ABC sheets
- Wong Pain scale (faces)
- McGrath & Breau Pain scale
- Bristol stool form
- Sleep chart
- Food diary
- Menstrual Cycle observation sheets (Gedye)

ABC Sheets

Antecedent (date, time, activity, location, others present)	Behaviour (describe the specific behaviour: pica & item, aggression, SIB where)	Consequence (reactions & interventions of peers & staff)	Reaction of individual afterwards

Gestures & Possible Causes

SOLUTION·S

High Pain Tolerance:

- hx of pain, chronic problem;
- delirium;
- neuropathies;
- genetic syndromes;
- fear of complaining.

SOLUTION·S

Sensory Integration Problems in Persons with Autism

Individual variations:

- hypersensitive;
- hyposensitive to touch, sound, light, foods (odours & textures);
- deferred pain (pain in one area, points to another location);
- selective receptivity (reacts differently to same stimuli on different occasions).

Gestures & Possible Causes

SOLUTION·S

Hand in mouth/throat:

- reflux/heartburn;
- dental pain/new teeth coming in;
- asthma;
- rumination;
- nausea.

Gestures & Possible Causes

Hand-biting:

- sinus problems;
- ear/Eustachian tube problems;
- wisdom teeth coming in;
- dental pain;
- paresthesia (numbness/tingling) in hand.

Gestures & Possible Causes

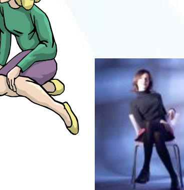
Biting objects:

- sinus problems;
- ear problems/otitis;
- dental pain.

Gestures & Possible Causes

Uneven sitting position:

- pain in the hips;
- pain in genital area: vaginitis; urinary infection; horseback riding; abuse;
- pain in rectal area: constipation; diarrhea; hemorrhoids; physical or sexual abuse.



Gestures & Possible Causes

Odd or excessive masturbation:

- prostatitis;
- vaginitis/ yeast infection;
- urinary infection;
- intestinal parasites/ pinworms;
- PTSD (“flashbacks”).

Gestures & Possible Causes

Waving fingers in front of eyes:

- cataracts;
- migraine;
- epilepsy/seizure;
- visual problem/”floaters”.

Waving head from side to side:

- visual problems.

Gestures & Possible Causes

Opposite hand or fingertip only handshake:

- pain in hand, arthritis;
- frightening previous setting/experience.

Gestures & Possible Causes

Walking on toes:

- arthritis in ankles, feet, hips, knees;
- heel pain/bone spur;
- tight heel cords.

Gestures & Possible Causes

Refusing to sit down:

- akathisia/side effects of medication;
- back pain;
- rectal pain;
- anxiety.

Gestures & Possible Causes

Intense rocking, preoccupied look:

- abdominal pain;
- headache;
- depression.

Gestures & Possible Causes

Stretching back/forward:

- atlanto-axial dislocation;
- reflux/heartburn;
- pain in hips;
- pain in lower back;
- dental pain.

Atlanto-Axial Dislocation

SOLUTION·S

Atlas (C1)

Dens

Axis (C2)

Atlas (the first cervical vertebra)

Axis (the second cervical vertebra)

Spinous Process

Transverse process

Vertebral body

C1 C2 C3 C4 C5 C6 C7 TI

Gestures & Possible Causes

Sitting down suddenly:

- atlanto-axial dislocation;
- cardiac problems;
- epilepsy/seizures;
- syncope/low BP;
- vertigo;
- otitis, equilibrium problems.

Gestures & Possible Causes

SOLUTION-S

Pica :

- general: OCD; hypothalamic problems; under stimulating environment; reflux;
- cigarettes: nicotine dependence; anxiety;
- glass: suicide;
- paint chips: lead intoxication;
- dirt: deficit in iron; minerals;
- feces: PTSD; psychosis;
- rocks, sticks, pieces of metal: endogenous opiate addiction.

Gestures & Possible Causes

Scratching :

- eczema;
- SE of medications;
- liver or kidney problems;
- scabies, lice, bedbugs.

Gestures & Possible Causes

Scratching stomach:

- Stomach pain: **constipation; gastritis; ulcer; pancreatitis; menstrual cramps;
- porphyria;
- gall bladder disease.

Gestures & Possible Causes

SOLUTION·S

Self-hug/self-restraint:

- pain;
- tic, Tourette syndrome;
- epilepsy/seizure;
- PTSD;
- paresthesia/tingling;
- sensory integration problems;
- genetic syndrome: Smith Magenis.

Gestures & Possible Causes

SOLUTION·S

Scratching/squeezing chest:

- respiratory problems : asthma; pneumonia;
- reflux;
- angina;
- costochondritis.

Gestures & Possible Causes

SOLUTION·S

Head-banging:

- general pain – various sources; constipation;
- specific pain: migraine; dental; otitis; sinusitis; mastoiditis; conjunctivitis (irritation in eye);
- tinea capitus;
- depression;
- epilepsy/seizure;

Other behaviours and Possible Causes

SOLUTION-S

"Obsessive" bathroom visits:

- urinary infection;
- prostate problem;
- constipation/diarrhea;
- diabetes ;
- genetic syndrome: Angelman Syndrome.

Other Behaviours and Possible Causes

SOLUTION-S

Now Serving 0001

TAKE A NUMBER 9359

Fatigue or "napping":

- sleep problems: insomnia; sleep apnea;
- diabetes;
- under stimulation environment/boredom;
- depression;
- thyroid problem (hypothyroid).

Other Behaviours and Possible Causes

SOLUTION-S

Insomnia or waking up at night:

- pain (arthritis, GERD, constipation);
- need to void: diabetes;
- nocturnal seizures;
- bad dreams: PTSD;
- discomfort: cold feet; wet diaper; sweating (menopause!);
- too much light in the window;
- other sensory issues.

solution·s

Other Behaviours and Possible Causes

Hitting others:

- chest pain, constipation, fracture/infection ("guarding");
- under stimulated environment/boredom;
- depression/mania/psychosis;
- seizure/epilepsy;
- frontal lobe syndrome.

Five Guiding Principles

- Person- centred
- Optimize QOL of the person
- Prevent CB from occurring
- Intervene on causes
- Teach replacement behaviours

Part A
Primary Care Provider Section

Name:
DOB:

1. REVIEW OF POSSIBLE MEDICAL CONDITIONS **[See also Preventive Care Checklist]**

Many medical conditions present atypically in people with developmental disabilities. In some cases the only indicator of a medical problem may be a change in behaviour or daily functioning. Consider a complete review of systems, physical exam, and necessary investigations until the cause of the behaviour change is identified.

Would you know if this patient was in pain? ☐ No ☐ Yes If yes, how does this patient communicate pain?
☐ Expresses verbally ☐ Points to place on body
☐ Expresses through non-specific behaviour disturbance (describe):
☐ Other (specify):

Could PAIN, injury or discomfort (e.g., fracture, tooth abscess, constipation) be contributing to the behaviour change? ☐ No ☐ Yes ☐ Possibly ____

Assess/Rule out:

☐ Medical condition giving rise to physical discomfort (e.g., rash or itch)

☐ Medication side effect	☐ Dysmenorrhea/Premenstrual syndrome
☐ Change in medication	☐ Peri-menopausal/menopausal (may start earlier)
☐ Allergies	☐ Musculoskeletal (arthritis, joints)
☐ Vision problem (e.g., cataracts)	☐ Osteoporosis
☐ Hearing problem	☐ Degenerative disc disease (DDD)
☐ Dental problem	☐ Spasticity
☐ Cardiovascular	☐ Neurological (e.g., seizures, dementia)
☐ Respiratory	☐ Dermatological
☐ Pneumonia	☐ Sensory discomfort (e.g., new clothes, shoes)
☐ GERD/Peptic ulcer disease/*H.pylori* infection	☐ Hypothyroidism
☐ Constipation, or other lower GI problems	☐ Diabetes (I or II)
☐ UTI	☐ Sleep problems/sleep apnea

☐ Other

Comments:

2. PROBLEMS WITH ENVIRONMENTAL SUPPORTS OR EXPECTATIONS
Review Caregiver Information *Identify possible problems with supports or expectations.*

☐ **Stress or change in the patient's environment?** – living situation, day program, family situation
☐ **Insufficient behavioural supports?**
☐ **Patient's disabilities not adequately assessed or supported?** (e.g., sensory and communication supports for patients with autism)
☐ **Insufficient staff resources?** (e.g., to implement treatment, recreational, vocational or leisure programs)
☐ **Inconsistencies in supports and staff approaches?**
☐ **Insufficient training/education of direct care staff?**
☐ **Signs of possible caregiver burnout?** (e.g., negative attitudes towards person, impersonal care, difficult to engage with staff, no or poor follow through in treatment recommendations)

Do caregivers seem to have inappropriate expectations associated with:

Recognizing or adjusting to identified patient needs	☐ Yes	☐ No	☐ Unsure
Over- or under-estimating patient's abilities (boredom or under-stimulation)	☐ Yes	☐ No	☐ Unsure

Comments:

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Part B Caregiver Section	Name: Date of Birth:

2.2: SUPPORT ISSUES? Are there any problems in this patient's support system that may contribute to his/her basic needs not being met?

- Does this patient have a ☐ **hearing** or ☐ **vision problem?** ☐ No ☐ Yes: If yes, what is in place to help him/her?
- Does this patient have a **communication problem?** ☐ No ☐ Yes: If yes, what is in place to help him/her?
- Does this patient have a problem with **sensory triggers?** ☐ No ☐ Yes: *If yes*, what is in place to help him/her?
  → *If yes*, do you think this patient's environment is ☐ over-stimulating? ☐ under-stimulating? or ☐ just right for this patient?
- Does environment seem **too physically demanding** for this patient? ☐ No ☐ Yes
- Does this patient have enough opportunities for **appropriate physical activities?** ☐ No ☐ Yes
- Does this patient have **mobility problems** or **physical restrictions?** ☐ No ☐ Yes: If yes, what is in place to help him/her? Does he/she receive physiotherapy?
- Are there **any supports or programs that might help this patient** and which are not presently in place? ☐ No ☐ Yes: If yes, please describe:

Caregiver comments:

Future Challenges…

SOLUTION·S

PREVENTION!!!

- dental care;
- vision & hearing;
- nutrition & exercise;
- screening: thyroid; osteoporosis; cancer; PAP; mammogram; high risk concerns (constipation, reflux);
- immunization/vaccines.

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

SOLUTION·S

Describe best practice in caring for adults with DD:

- general issues (9);
- physical health issues (12);
- behavioural and mental health issues (10).

Tools for the Primary Care of People with DD

SOLUTION-S

- Developed to assist PCPs in "how-to" of applying guidelines.
- Electronic versions available at:
  www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx
- Future tools for caregivers (group home staff, family members) and people with DD.

Key Messages

SOLUTION-S

"Problem behaviours" or "challenging behaviours" (problems for caregivers, incl. PCP's) are ways people with DD communicate distress.

= "**distressed behaviours**"

To consider… (Ryan, 2001)

SOLUTION-S

- Challenging behaviour (CB) may indicate a health problem (physical or mental).
- These same CBs may mean different things at different times.
- EVERY CB means something!
- Pain that you can control is preferable to pain that is out of control!
- Often, our clients have learned NOT to complain (M*).

Intensive Evaluation needed!

SOLUTION·S

- Data collection: many aspects!
- Taking a thorough history.
- Review of systems.
- Physical exam.
- Investigations.

SOLUTION·S

Questions?

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