DECONSTRUCTING DYSPNEA:
A CONCEPTUAL FRAMEWORK FOR MANAGING BREATHLESSNESS IN END STAGE LUNG DISEASE

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Terms of Reference and Challenges

- **Dyspnea** – when standard interventions for underlying lung disease, its complications and co-morbidities exhausted
- **End-stage lung disease**: severity and prognosis
- Medication use **controversies**
  - e.g. opioids, anxiolytics, oxygen
- **Limited literature** on very extreme spectrum
- Ethical considerations to research studies
- Presentation: JRE-specific; off label; evolving
Managing Dyspnea in End-Stage Lung Disease

• Pulmonary Rehabilitation Medicine
  - multidisciplinary approach
  - holistic care
  - emphasis on improving quality of life

• Lessons in symptom management from Palliative Care

• Lessons from patients with end-stage lung disease

• Evolution of Dyspnea Management Protocols
Patient Population (JRE)

- COPD: FEV1 = 11 – 25% predicted
- Lung Cancer – Stage IV
- Interstitial Lung Disease (PaO₂ <50; DCO<30%)
  - Idiopathic; Radiation Fibrosis; Collagen vascular disease
- Bronchiectasis
- Pulmonary Hypertension (rapid desaturation)
- Amyotrophic Lateral Sclerosis
- Multiple lung pathologies, including Illicit Drug Use
- Lung Disease
New definition of Pulmonary Rehabilitation - ATS and ERS 2013

“Pulmonary rehabilitation is a comprehensive intervention based on a thorough patient assessment followed by patient-tailored therapies, which include, but are not limited to, exercise training, education and behavior change, designed to improve the physical and emotional condition of people with chronic respiratory disease and to promote the long-term adherence of health-enhancing behaviors.”
Primary Goals of Pulmonary Rehabilitation

- To restore the patient to the highest level of independent function.
- “There is a better way to live with breathlessness because breathing is not an option.”
- Provide teaching, tools and techniques to:
  - Reduce breathlessness
  - Improve exercise tolerance
  - Increase functional capacity
  - Enhance quality of life
Common problem affecting up to half of patients admitted to acute, tertiary care hospitals and one quarter of ambulatory patients

Definition: a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity
Dyspnea

- Breathless
- Short of breath
- Hard to breathe
- Air hunger/unsatisfied inspiration
- Tightness

Or:

- Takes longer to do a task (e.g. eat, dress)
- Tires more easily
- No Energy
Approach to Assessment of Dyspnea*

- Functional capacity – MRC scale
- When: walk me through a typical day
- Intensity: tell me on a scale of 0-10 (where 0=no breathlessness and 10=absolute worst)
- Tell me what triggers your breathlessness
- What do you do to feel better? Are you using your oxygen at that point?

*JRE approach
Approach to Assessment of Dyspnea

- At rest
- Talking
- Eating
- Dressing
- Bathing/showering
- Having a bowel movement
- Walking across the room, uphill or on an incline
- Walking upstairs
- Other activities: patient-specific (e.g. meal preparation)
- Any dyspnea crises (8-10/10): when, where, what, why
Conditions that make dyspnea worse

- Cough – phlegm, quantity, airway clearance regimen, coughing techniques
- Nasal congestion/sinus disease
- Dry nasal mucosa/bleeding (from nasal cannula)
- GI symptoms: dry mouth, GERD/reflux/aspiration, constipation, bloating, overweight, underweight
- Poor nutrition; dehydration
- Poor sleep
- R-CHF, pulmonary hypertension, IHD: palpitations, chest pain, ankle swelling, syncope
- Mood: anxiety, agitation, depression, worry; social isolation; loss of purpose; fear
- Renal failure

MEDICATION: e.g. inhaler/method of use/timing; O2
Education and Assessments

- Oxygen prescription/non-invasive ventilation
- Nutrition: Food content, acquisition, preparation, consumption
- Sleep hygiene
- Coping strategies/psychosocial issues/leisure
- Exercise prescription: Breathing, range of motion, strengthening, endurance, activity precautions
- Community supports: FDr, Home Care, Palliative Care Services
- Action Plans: - to accomplish the patient’s goals/activities
  - Medications on hand: infections, CHF, IHD, symptom control, crisis
  - Emergency Response Information Kit with Goals of Care, health and contact information
  - Anticipated Death at Home Form; Physician order sheet on fridge
Role of the Respiratory Therapist

- Education
- Oxygen prescription and reassessment
- Sleep hygiene and non-invasive ventilation
- Review of medication
- Infection control
- Breathing retraining
- Coughing techniques
- Nasal and sinus congestion management strategies
- Infection control
- Crisis prevention and intervention
- Support
- Liaise with other allied health care and MDs
Role of the Occupational Therapist

- Education
- Home assessment and re-organization
- ADLs with pulmonary hypertension activity precautions
- Pacing and energy conservation
- Cognitive assessments
- Aids for living: e.g. 4WW, commode, shower
- Liaise with other allied health care and MDs
Role of the Physiotherapist

- Education
- Exercise prescription
  - Breathing exercises
  - Range of motion
  - Strengthening exercises: upper body; lower body
  - Endurance
  - Activity precautions
- Fall risk assessment and recommendations
- Pacing
- Chest physiotherapy; airway clearance and coughing techniques
- Reassessment of exercise prescriptions
Pulmonary Hypertension Activity Precautions

- Avoid activity that increases intrathoracic pressure or venous return to the right/left side of the heart
- Stop activity if symptomatic (dyspnea >5-6/10; dizzy/light-headed, increased cough, hemoptysis)
- O2 desaturation to ?; HR up to ?
- Avoid valsalva manoeuvres (avoid constipation)
- No bending/leaning over (with head below heart level)
- No squatting
- Do not hold arms above shoulder height
- Change body position slowly (e.g., sit up in bed, then hang feet over side of bed, then stand up, then move)
- Weight limitation for carrying in hands/arms
Role of the Social Worker

- Education
- Community supports
- Optimization of home living situation
- Patient and caregiver dynamics
- Coping strategies
Other Team Members

- Nurse
- Pharmacist
- Recreation therapists — leisure, distraction, purpose, socialization
- Psychologists
- Spiritual Care
- Palliative Care
- FAMILY DOCTOR; Nurse Practitioner
- OTHER MEDICAL SPECIALISTS
Setting goals

- By the team members:
  - Reverse knowledge deficit
  - Increase functional activity tolerance
  - Use oxygen
  - Pace

- By the patient:
  - “To be able to walk a block outside my home with my husband”
  - “To flip pancakes for my grandson”
  - “To wear my wedding rings”
  - “To dress myself”
Pulmonary rehab approaches for control of dyspnea

- **Breathing retraining**
  - Pursed-lip breathing (for COPD)
  - Diaphragmatic (abdominal) breathing (for COPD)
  - Application to panic control

- **Pacing**

- **Exercise program** (breathing, strengthening, endurance)

- **Improvement in ambulation** (e.g. use of a 4WW) and other types of physical activity (HRQL)

- **O2 prescription**: rest; activity

- **Use of medications**: take control of the breathlessness before it takes control of you – e.g. pre-activity bronchodilator
1. **Baseline Dyspnea** – refractory dyspnea
2. **Incident Dyspnea** – anticipated as a result of an activity
3. **Crisis Dyspnea** – unanticipated
Management of Dyspnea

* Long acting medication
** Fast onset, short acting medication
*** Crisis management

Diagram showing daily activities and dyspnea levels with annotations for medication timing.
To Reduce **Baseline Dyspnea:**
Reset the sensitivity of the “Barometer for Breathing”

- **Start low** with *immediate release oral* medications
- E.g. Morphine 1-2.5 mg po bid (am and early afternoon); or hydromorphone 0.25 mg po twice per day; and q2-4h prn for increased baseline dyspnea (“bad day”)  
- Base dosing strategy on patient’s day: e.g. worse in pm  
- Increase frequency (tid before meals) and then dose  
- Can introduce *long-acting* hydromorphone (hydromorph-contin) once dose reaches 3 mg or *long-acting* morphine once dose is 10 mg  
- Consider fentanyl patch 12 mcg once total dose is 8 – 14 mg hydromorphone or equivalent  
- **DO NOT USE FENTANYL PATCH OR LONG-ACTING OPIATES** if patient is narcotic-naïve

- JRE
Mucosal Drug Delivery: To Manage Incident and Crisis Dyspnea

**Sublingual or Buccal:**
- medication needs to be held in mouth (especially fentanyl)
- do not swallow
- Fast onset ~5 – 10 minutes

**Intranasal: Mucosal Atomization Device (MAD™)**
- Faster onset ~2-3 minutes?
- 1/3 ml ideal volume
- 1 ml maximum volume
- Particle size: 30-100 microns
- Re-usable; inexpensive
- Achieve serum drug levels comparable to injection

See: intranasal.net
To Reduce Incident Dyspnea:

Treat before activity that will cause breathlessness

- Use medications for injection via mucosal route (sublingual/buccal or intranasal)
- Patient to self-manage 10 min prior to activity using fast onset, short duration narcotic, e.g. fentanyl, in pulmonary parenchymal disease

**NOTE:** if fentanyl swallowed, it is degraded and therefore inactive; it must be HELD in mouth

- Patients with ALS/neuromuscular disorders seem to need a longer acting (slower offset) narcotic: therefore I use hydromorphone in small volumes (many are NPO)
- Pharmacy prefills syringes with a selected dose (+/- colour-coded)
- One syringe prior to lower intensity activity and two syringes for higher intensity activity
- Patient/caregiver provides frequent regular feedback to MD regarding efficacy of this approach so that dose and Rx’s are adjusted to meet escalating needs in a timely manner
- Other factors: O2 dose; NIV
**Sublingual fentanyl** *(50 mcg/ml) for Incident Dyspnea (JRE)*

- Hold in mouth 10 minutes pre-activity: *don’t swallow*

- **Aim: not drowsy**

(*Off-label use*)

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>INTENSITY</th>
<th>DOSE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talking</td>
<td>Low</td>
<td>6.25 mcg (0.125 ml)</td>
</tr>
<tr>
<td>Eating</td>
<td>Low</td>
<td>6.25 mcg (0.125 ml)</td>
</tr>
<tr>
<td>Washing your face</td>
<td>Low</td>
<td>6.25 mcg (0.125 ml)</td>
</tr>
<tr>
<td>Getting out of bed</td>
<td>Moderate</td>
<td>12.5 mcg (0.25 ml)</td>
</tr>
<tr>
<td>Ambulating</td>
<td>Moderate</td>
<td>12.5 mcg (0.25 ml)</td>
</tr>
<tr>
<td>Having a bowel movement</td>
<td>High</td>
<td>25 mcg (0.50 ml)</td>
</tr>
<tr>
<td>Bathing</td>
<td>High</td>
<td>25 mcg (0.50 ml)</td>
</tr>
<tr>
<td>Exercise</td>
<td>Moderate - High</td>
<td>12.5 - 25 mcg</td>
</tr>
</tbody>
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Desired Feature to Manage Crisis Dyspnea: ➔ It works NOW!

- Conducive to patient’s sense of self-efficacy and independence
- Patient can use independently for self-management
- Care-giver can administer
- Simple – easy to learn and apply
- Fast onset
- Effective
- Flexible - to meet the patient’s varying needs through the day and night
- Readily adaptable as patient’s condition deteriorates (or improves)
- Can be readily escalated for terminal palliation
Crisis Dyspnea

- Immediately stop activity
- Don’t crowd patient (avoid being in front of patient)
- Coach change in breathing pattern
- Sublingual or intranasal narcotic q10min until dyspnea settles
- +/- Sublingual lorazepam 0.5 – 2.0 mg tabs or liquid q2-4h prn for anxiety
- +/- mucosal nozinan OR haldol OR olanzepine prn for agitation
- Check oxygen flow +/- increase flow rate; NIV
- +/- fan
- +/- cold cloth for back of neck/shoulders
Other Action Plans

- **Chest Infections**
- **Airway clearance regimen**: >2 tbsp sputum/day; PCF<270 L/min
- **CHF**
- **Dizziness**: pulmonary hypertension precautions; screen for falls
- **Chest pain – IHD**: e.g. pre-activity NTG
- **GERD**: education re GERD precautions; H2/PPI + prn Gaviscon ES
- **Constipation**: enact action plan if no bowel movement that day (DON’T WAIT 3 DAYS); preventive measures
- **Anxiety/Panic**: change breathing pattern, fan, close eyes, visualization +/- anxiolytic

**PATIENT AND CAREGIVER TO KNOW WHO TO CALL FOR HELP/ADVICE:**
Home Care RRT, NP, FD or Community Care Access After Hours (RRT and palliative RN on call in Edmonton zone 24/7)
Summary of Approach: Multidisciplinary

- Define patient’s goals of care; Advanced Health Care Directive
- Therapeutic management of:
  - Respiratory disease: pulmonary parenchymal; neuromuscular
  - Comorbidities: CHF, GERD, Sinus disease, Constipation, IHD
- Modifications to:
  - Environment
  - Improve activity tolerance: exercise prescription
- Educate: disease, goals, management and action plans
  - Patient and Caregivers
  - Other health care providers: Community, ER and Hospital
- Programming: outpatient; inpatient; n:1
Case 1 – 82 yo COPD

- MRC 5/5; COPD; bronchiectasis; IgG deficiency
- Hiatal hernia
- FiO2 3 lpm at rest; 4 lpm with activity
- Inhalers: nebulized combivent and mucomyst; ventolin prn → a/c using MBT pre-activity
- → Acapella; huff coughing
- Domperidone bid → pre-meals
- Anxiety: ativan before going out of house;
- Poor sleep: trazodone qhs
Case 1 – 82 yo COPD

- Admitted to Glenrose for Geriatric Rehab x 6 weeks: pneumonia; SLP assessment: aspiration risk
- Stops airway clearance regimen and pre-activity ventolin
- CRISIS after 1 week at home: referral for hospice; starts morphine syrup 1 mg tid
- Able to cope at home
- RRT, FDr, Resp-MD follow up
Case 1 – 82 yo COPD: dyspnea scores (ESAS)

- Rest: 0
- Talking: 4-7
- Eating: 0-1 (no appetite); denies cough
- Dressing: 7
- Bathing: 8 on FiO2 3 lpm
- B.M.: 0
- Chores: (meals): 7 (no pre-activity ventolin; same FiO2)
- Walking in house: 4-7
- To car outside: 10/10 with lorazepam and ventolin
- Crisis: to daughter’s for dinner prior weekend
Case 2 – 54 yo M ILD

- COPD, ILD, R-CHF, IHD, PH, CRF, PVD
- Recent ex-smoker
- Not a lung transplant candidate
- FiO2 15 lpm - Respiratory Benefits exception
- Inhalers
- Sinus issues
- Cough
- Back pain
- Lives alone in a house; no supports; MRC 5/5
Case 2 – 54 yo M ILD

- Fentanyl patch for chronic pain and baseline dyspnea
- Hydromorphone prn for breakthrough pain
- Subling fentanyl pre-activity and crisis
- R-CHF treatment; cellulitis/lymphedema
- Home Care Support: RRT, RN, RSW, OT, PT, RD, Resp-MD
- August 2012 – October 2013: at home
- October 2013: admitted to RAH with delirium, ARF (creat 700); independent use of prefilled fentanyl syringes
- Transferred to TPCU and died March 2014
Thank you!

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