Can we “see” subjective symptoms of distress?

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Objectives

- Describe the reliability of symptom self-report from sick, or terminally ill, or cognitively impaired patients
- Describe bio-behavioral frameworks for distress recognition
- Describe behavioral correlates of pain and dyspnea

Definitions

- Pain – an unpleasant sensory or emotional experience associated with actual or potential tissue damage or described in terms of such damage *
- Pain is whatever the patient says it is

*IASP Subcommittee on Taxonomy, 1980
Definitions

- Dyspnea – a person’s awareness of uncomfortable or distressing breathing that can only be known through the person’s report
- Respiratory distress* – an observed corollary to dyspnea; the physical and emotional distress associated with respiratory dysregulation

* Campbell, Crit Care Clinics, 2004

Prevalence of pain across terminal illness (Solano et al. 2006)

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Prevalence %</th>
<th># of studies</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>35-96</td>
<td>19</td>
<td>10,379</td>
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<tr>
<td>AIDS</td>
<td>63-80</td>
<td>3</td>
<td>942</td>
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<tr>
<td>Heart disease</td>
<td>41-77</td>
<td>4</td>
<td>882</td>
</tr>
<tr>
<td>COPD</td>
<td>34-77</td>
<td>3</td>
<td>372</td>
</tr>
<tr>
<td>Renal disease</td>
<td>47-50</td>
<td>2</td>
<td>370</td>
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</table>

Prevalence of dyspnea across terminal illnesses (Solano et al. 2006)

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Prevalence %</th>
<th># of studies</th>
<th>N</th>
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</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>10-70</td>
<td>20</td>
<td>10,029</td>
</tr>
<tr>
<td>AIDS</td>
<td>11-62</td>
<td>2</td>
<td>504</td>
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<tr>
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<td>60-88</td>
<td>6</td>
<td>948</td>
</tr>
<tr>
<td>COPD</td>
<td>90-95</td>
<td>4</td>
<td>372</td>
</tr>
<tr>
<td>Renal disease</td>
<td>11-62</td>
<td>2</td>
<td>334</td>
</tr>
</tbody>
</table>
Prevalence of confusion across terminal illnesses (Solano et al. 2006)

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Prevalence</th>
<th># of studies</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>6-93</td>
<td>19</td>
<td>9154</td>
</tr>
<tr>
<td>AIDS</td>
<td>30-65</td>
<td>2</td>
<td>?</td>
</tr>
<tr>
<td>Heart disease</td>
<td>18-32</td>
<td>3</td>
<td>343</td>
</tr>
<tr>
<td>COPD</td>
<td>18-33</td>
<td>2</td>
<td>309</td>
</tr>
<tr>
<td>Renal disease</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Errors in patient symptom intensity self-reporting (Garyali, et al. 2006)

- Retrospective analysis of patient ESAS scores with subsequent physician assessment and score clarification
- Sample – 60 cancer patients receiving outpatient palliative care
- Physician-patient agreement
  - Pain = 68%
  - Dyspnea = 70%
- Conclusion – Clinicians should check patient accuracy on assessment tool completion

Impaired thinking in sick patients

- Sick hospitalized patients were compared to controls
  - All participants had MMSE ≥ 24
  - Sick patients had Karnofsky ≤ 50
  - Piagetian tasks of judgment were completed
- Results
  - No differences in age or gender
  - Sicker patients responded correctly to fewer tasks compared to controls
  - Sick patients performance similar to children < 10 years

Cognitive skills necessary for symptom reporting

- Able to *interpret* sensory stimuli
- Able to pay *attention* to instructions and *concentrate* to form a report
- Able to *communicate*
- Able to *remember* previous report

Common pain/dyspnea assessment tools

- Numeric rating system – 0-10
- Visual analog scale – vertical or horizontal line anchored from 0-10 or 0-100 mm
- Wong-Baker FACES - pain
- Modified Borg – category-ratio scale using descriptive terms to anchor responses to dyspnea after exercise

Wong-Baker FACES scale

![Wong-Baker FACES scale diagram]
Vertical Dyspnea Visual Analog Scale

Modified Borg categorical scale

<table>
<thead>
<tr>
<th>SCALE</th>
<th>SEVERITY</th>
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<tbody>
<tr>
<td>0</td>
<td>No Breathlessness* At All</td>
</tr>
<tr>
<td>0.5</td>
<td>Very Very Slight (Just Noticeable)</td>
</tr>
<tr>
<td>1</td>
<td>Very Slight</td>
</tr>
<tr>
<td>2</td>
<td>Slight Breathlessness</td>
</tr>
<tr>
<td>3</td>
<td>Moderate</td>
</tr>
<tr>
<td>4</td>
<td>Some What Severe</td>
</tr>
<tr>
<td>5</td>
<td>Severe Breathlessness</td>
</tr>
<tr>
<td>6</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Very Severe Breathlessness</td>
</tr>
<tr>
<td>8</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Very Very Severe (Almost Maximum)</td>
</tr>
<tr>
<td>10</td>
<td>Maximum</td>
</tr>
</tbody>
</table>

Measuring pain or respiratory distress in patients with cognitive impairment

- Gold standard instruments
  - Numeric report
  - Dyspnea visual analog scale
  - Modified Borg

- Observation tools
  - Needed
Pain behaviors during painful procedures, n = 5957, 169 hospitals, U.S., Canada, England, Australia

- Procedures
  - Turning
  - Suctioning
  - CVP placement
  - Drain removal
  - Femoral sheath removal
  - Wound care

- Behaviors
  - Grimacing
  - Rigidity
  - Wincing
  - Shutting eyes
  - Verbalization
  - Moaning
  - Clenching fists

Puntillo et al. Critical Care Med, 2004

Pain Behavior Scales

- Dementia scales
  - Discomfort scale for Alzheimer Type (DS-DAT)
  - Assessment of Discomfort in Dementia (ADD)
  - Pain Assessment in Advanced Dementia (PAINAD)
- Checklist of Nonverbal Pain Indicators
- And others

A theoretical model of respiratory distress

- Autonomic nervous system
- Pulmonary Stress Behaviors
  - Tachypnea
  - Tachycardia
  - Accessory muscle use
  - Nasal flaring
  - Paradoxical breathing

Campbell, Heart & Lung, 2008
Subcortical appraisal

Conscious and unconscious responsivity

Subcortical appraisal - amygdala

- Produces an array of **innate, non-volitional, universal** fear responses
  - Facial expression
  - Vocalization
  - Motor response
  - Restlessness or freezing
  - Autonomic nervous system activation
Amygdala activation by an asphyxial threat

- Neuroimaging studies (PET or fMRI)
  - Healthy volunteers
  - Induced dyspnea
    - Inhaled CO₂
    - Inspiratory loading
  - Subcortical activation
    - Insula
    - Amygdala
  - Volitional breathing deactivation


Facial Expression: Fear

Fear Joy

Anger Disgust
Fear and Pulmonary stress behaviors across cognitive states

Design

- Descriptive, comparative, time-series
  - Systematic observations via capnograph/oximeter and videotape during a mechanical ventilation weaning trial
  - Baseline measures collected for 10 minutes pre-wean
  - Wean measures collected for up to 30 minutes
  - Subject asked to report emotion experienced after weaning trial concluded
Primal emotion facial expressions

Sample and inclusion criteria
- 12 adult men and women
  - Conscious
  - Undergoing first ventilator weaning trial
  - At-risk for weaning trial failure
  - Intact vs. mild vs. moderate cognitive impairment
    - Severe impairment excluded

Sample characteristics
- Five men and seven women
  - African-American 83%
  - 42-80 y/o (mean = 62.5 ± 13.8)
  - Intact cognition 50%, mild 33%, moderate 17%
Results

- Autonomic responsiveness
  - Tachycardia/tachypnea (n = 12, 100%)
  - Accessory muscle use (n = 7, 58%)
  - Paradoxical breathing (n = 4, 33%)
  - Nasal flaring (n = 3, 25%)
- Fear
  - Displayed (n = 7, 58%)
  - Reported (n = 4/10, 40%)
  - Displayed and reported (n = 2/7, 29%)
Conclusion

- Presence and severity of an asphyxial threat activates and mediates the pulmonary stress response and fear
- Gender influences fear reporting
- Asphyxia produces an innate, non-volitional, array of observable behaviors that signify respiratory distress

Application to Practice

- Generation of an observation instrument for assessment of respiratory distress

Psychometric Testing of a Respiratory Distress Observation Scale (RDOS)
Purpose

- To establish internal consistency and construct validity of a new instrument to measure the presence and intensity of respiratory distress for patients unable to self-report
  - Cronbach’s alpha
  - Convergent, discriminant validity

Respiratory Distress Observation Scale

<table>
<thead>
<tr>
<th>Variable</th>
<th>2 points</th>
<th>1 point</th>
<th>0 points</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart rate per minute</td>
<td>Baseline to &lt;5 beats</td>
<td>Baseline + 5-10 beats</td>
<td>Baseline + &gt;10 beats</td>
<td></td>
</tr>
<tr>
<td>Respiratory rate per minute</td>
<td>Baseline to &lt;3 breaths</td>
<td>Baseline + 3-6 breaths</td>
<td>Baseline + &gt;6 breaths</td>
<td></td>
</tr>
<tr>
<td>Restlessness</td>
<td>None</td>
<td>Infrequent, subtle movements</td>
<td>Frequent movements</td>
<td></td>
</tr>
<tr>
<td>Accessory muscle use: rise in clavicle during inspiration</td>
<td>None</td>
<td>Slight rise</td>
<td>Pronounced rise</td>
<td></td>
</tr>
<tr>
<td>Grunting at end-expiration: guttural sound</td>
<td>None</td>
<td>Present</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nasal flaring: involuntary movement of nares</td>
<td>None</td>
<td>Present</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of fear</td>
<td>None</td>
<td>Eyes wide open, facial muscles tense, brow furrowed, mouth open</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Sample

- 70 men and women from a pulmonary rehabilitation clinic
  - convergent validity: dyspnea report vs. respiratory distress behaviors
- 70 men and women orthopedic surgery inpatients
  - discriminant validity: respiratory distress vs. pain
- 70 men and women healthy normal subjects
  - discriminant validity: respiratory distress vs. comfortable breathing
Results

• Internal Consistency (n = 210)
  • Alpha = .78
  • Item-total correlations
    • Heart rate .447
    • Respiratory rate .663
    • Restlessness .342
    • Accessory muscle .603
    • Grunting .533
    • Nasal flaring .438
    • Fearful expression .558

Results

• Correlations (n = 210)
  • RDOS (behavior) – DVAS (report)
    • (r = .740, p = .000)
  • RDOS (behavior) – SpO2 (oxygen saturation)
    • (r = -.688, p = .000)

Results: Convergent validity

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>SpO2</td>
<td>90.3</td>
<td>2.8</td>
<td>79-100</td>
</tr>
<tr>
<td>DVAS</td>
<td>52.7</td>
<td>25.8</td>
<td>0-100</td>
</tr>
<tr>
<td>RDOS</td>
<td>4.8</td>
<td>2.9</td>
<td>0-12</td>
</tr>
</tbody>
</table>

RDOS – DVAS Pearson r = .389, p = .001
RDOS – SpO2 Pearson r = -.240, p = .045
Mean SpO₂, RDOS, DVAS, and numeric pain scores across study groups

<table>
<thead>
<tr>
<th>Study groups</th>
<th>SpO₂ % (SD)</th>
<th>RDOS (SD)</th>
<th>DVAS (SD)</th>
<th>Pain Score (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dyspnea (n=70)</td>
<td>90 (2.8)</td>
<td>4.83 (2.9)</td>
<td>52.67 (25.8)</td>
<td>-</td>
</tr>
<tr>
<td>Pain (n=70)</td>
<td>97.6 (1.7)</td>
<td>0.46 (0.96)</td>
<td>1 (5)</td>
<td>4.89 (3)</td>
</tr>
<tr>
<td>Healthy (n=70)</td>
<td>99 (1)</td>
<td>0.99 (0.94)</td>
<td>0.66 (3)</td>
<td>-</td>
</tr>
</tbody>
</table>

(F(2,207) = 119.84, p= .000) (F(2,207) = 268.2, p = .000)

Conclusions

- RDOS has internal consistency
  - May be improved with variable insertion
    - Paradoxical breathing

- RDOS is a valid indicator of respiratory distress behaviors in subjects who reported dyspnea

- RDOS discriminates respiratory distress from pain

Psychometric testing of a revised RDOS

- Design – Descriptive, correlational, prospective
- Sample –
  - Patients referred for inpatient palliative care consultation or admission to inpatient hospice
  - Patients with one or more of
    - Pneumonia
    - Lung cancer
    - COPD
    - Heart failure
Psychometric testing of revised RDOS

- **Method**
  - Patients are observed and RDOS scored at initial assessment
  - **Additional measures**
    - Self-reported dyspnea – Yes or No
    - Self-reported VAS score
    - SpO₂ and et-CO₂
    - Opioid and/or Benzodiazepine dosing
    - Consciousness and cognition scoring
    - Palliative Performance Scale score

Preliminary Findings

- Patients with PPS <30% are unable to self-report about dyspnea (p <.001)
- Of 10 patients who could respond to "yes" or "no" query about shortness of breath only 4 could quantify using VAS
- There is a trend toward fewer distress behaviors in patients with declining consciousness

In summary

- There is preliminary evidence to support behavioral assessment of respiratory distress
- Fear behaviors may characterize the affective dimension
- Self-report should be elicited whenever possible
- Behavioral assessment may be more reliable than proxy opinion