Introduction to Palliative Care

Małgorzata Krajnik
Chair of Palliative Care
Nicolaus Copernicus University,
Collegium Medicum in Bydgoszcz

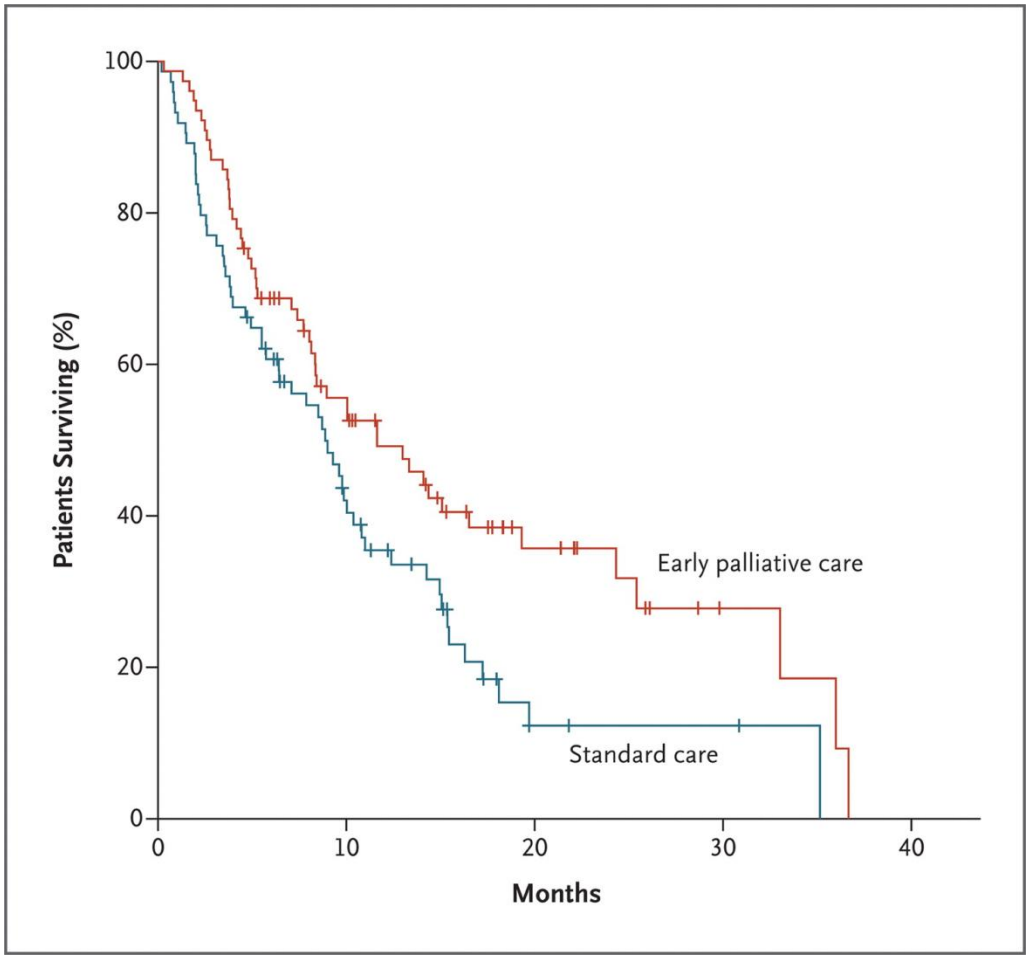
WHO definition of palliative care (2002)

- Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the **prevention and relief of suffering** by means of **early identification** and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care (1):

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;

Temel et al. Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer. *New England Journal of Medicine 2010; 363:*733-742



„Despite receiving less aggressive end-of-life care, patients in the palliative care group had significantly longer survival than those in the standard care group (median survival, 11.6 vs. 8.9 months; P=0.02)”

Breathlessness in Palliative Care

Małgorzata Krajnik
Chair of Palliative Care
Nicolaus Copernicus University,
Collegium Medicum in Bydgoszcz

1. Definition

- Dyspnea is “a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary”.

  (*The American Thoracic Society 1999)*

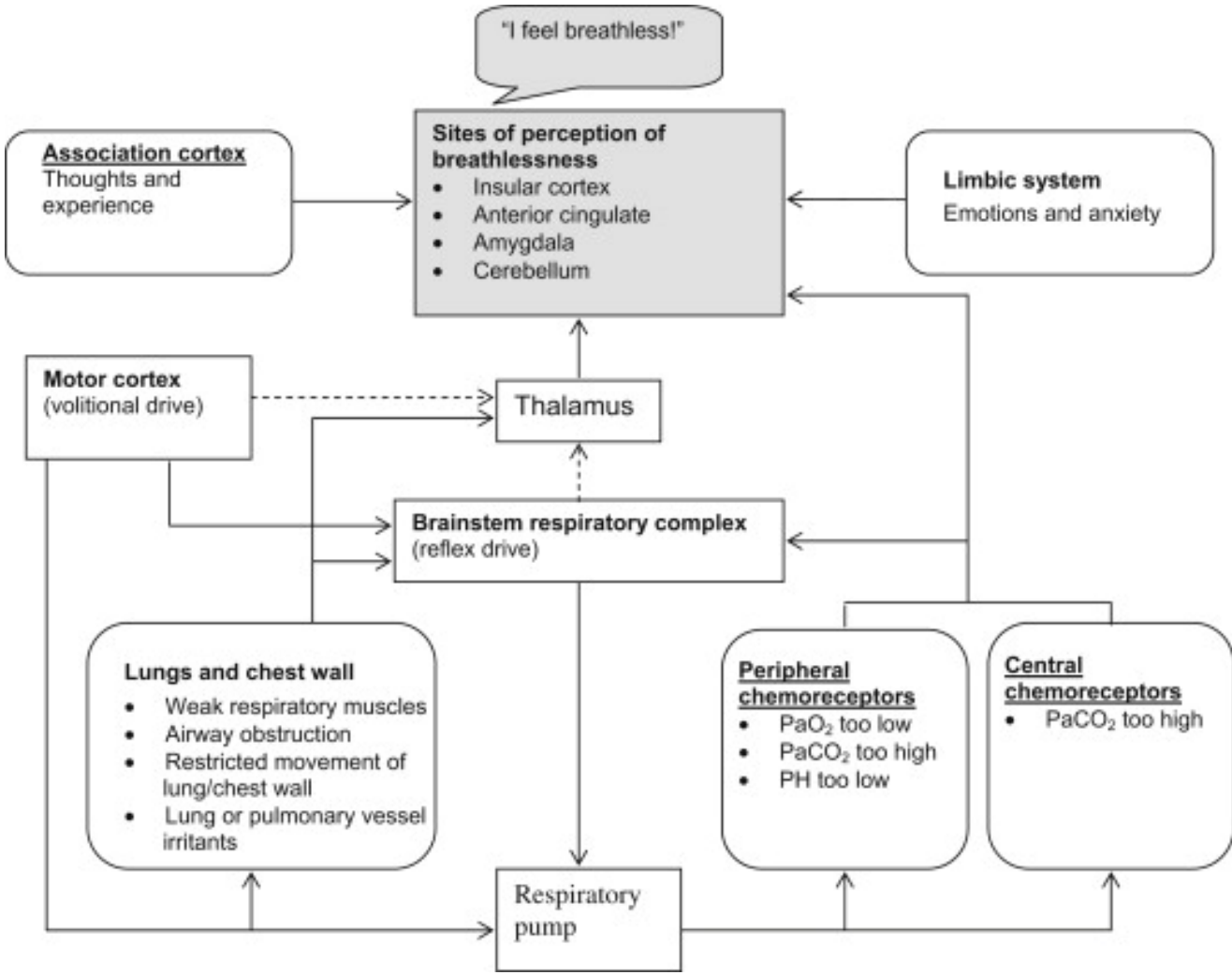
Pathophysiologically:

Dyspnea due to:

•increased load requiring greater respiratory effort (e.g., obstruction),

•an increase in the proportion of respiratory muscle required to maintain a normal workload (e.g., weakness),

•increase in ventilator requirements (e.g. fever, anemia).



Moosavi & Booth., 2011

How patients describe dyspnea?

- *I feel…* That I am smothering
- My breathing requires effort
- I cannot take a full breath
- I feel that my breath stops
- My chest feels tight
- I cannot get enough air
- I feel that I am suffocating
- My breathing is fast
- I cannot stop thinking about my breathing

[Kamal et al. J Palliat Med. 2011; 14(10): 1167–1172].

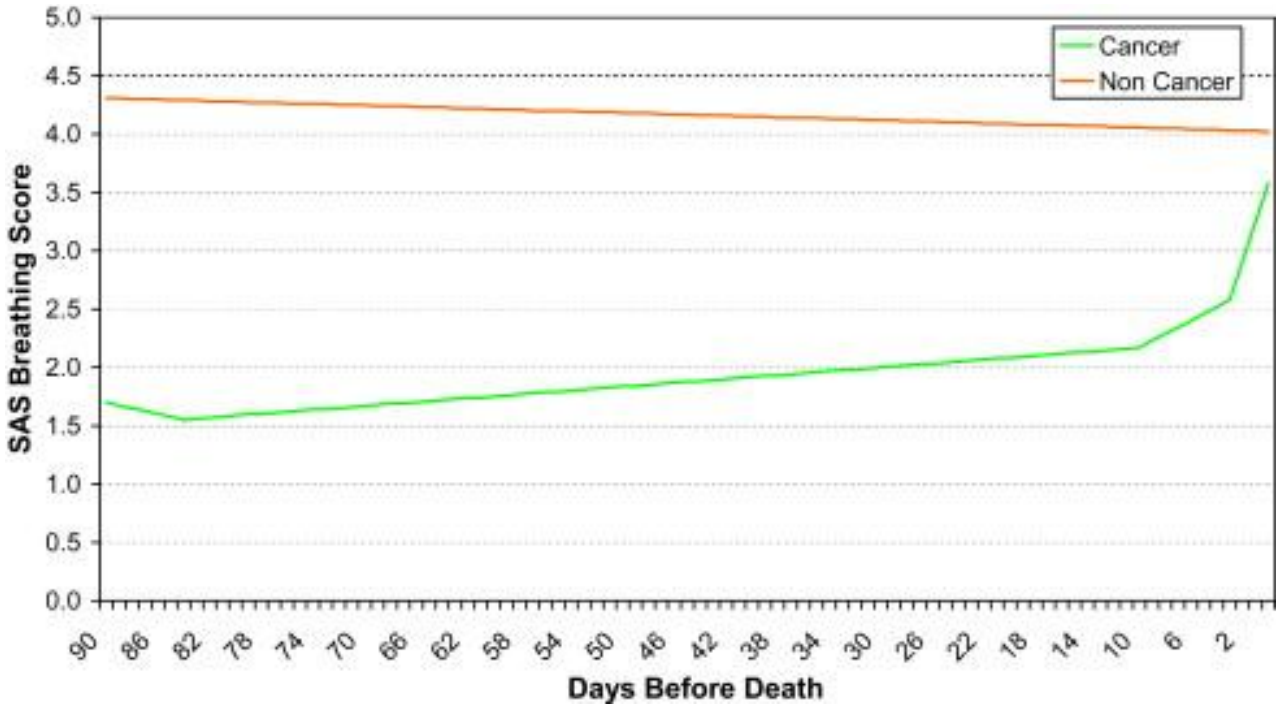
2. Incidence

Dyspnea is experienced at some point by most patients with advanced cancer, heart failure, and chronic lung disease and in the last 3 days of life in the imminently dying.

Cancer: 10-70%
COPD, Heart failure: 60-95%
ALS: almost 100%

¼ cancer patients with no known cardiopulmonary process (e.g., local cancer involvement, pleural effusions, pulmonary infections) experience dyspnea!

Trajectory of breathlessness



Currow et al.
J Pain Symptom Manage
2010;39:680-90.

Only 11.4% of patients receiving end-of-life care report “no breathlessness.”

In cancer patients with no known cardiopulmonary disorder, both prevalence and severity of dyspnea increase significantly as death approaches

Causes: spiritual suffering, anxiety, fatigue, cachexia

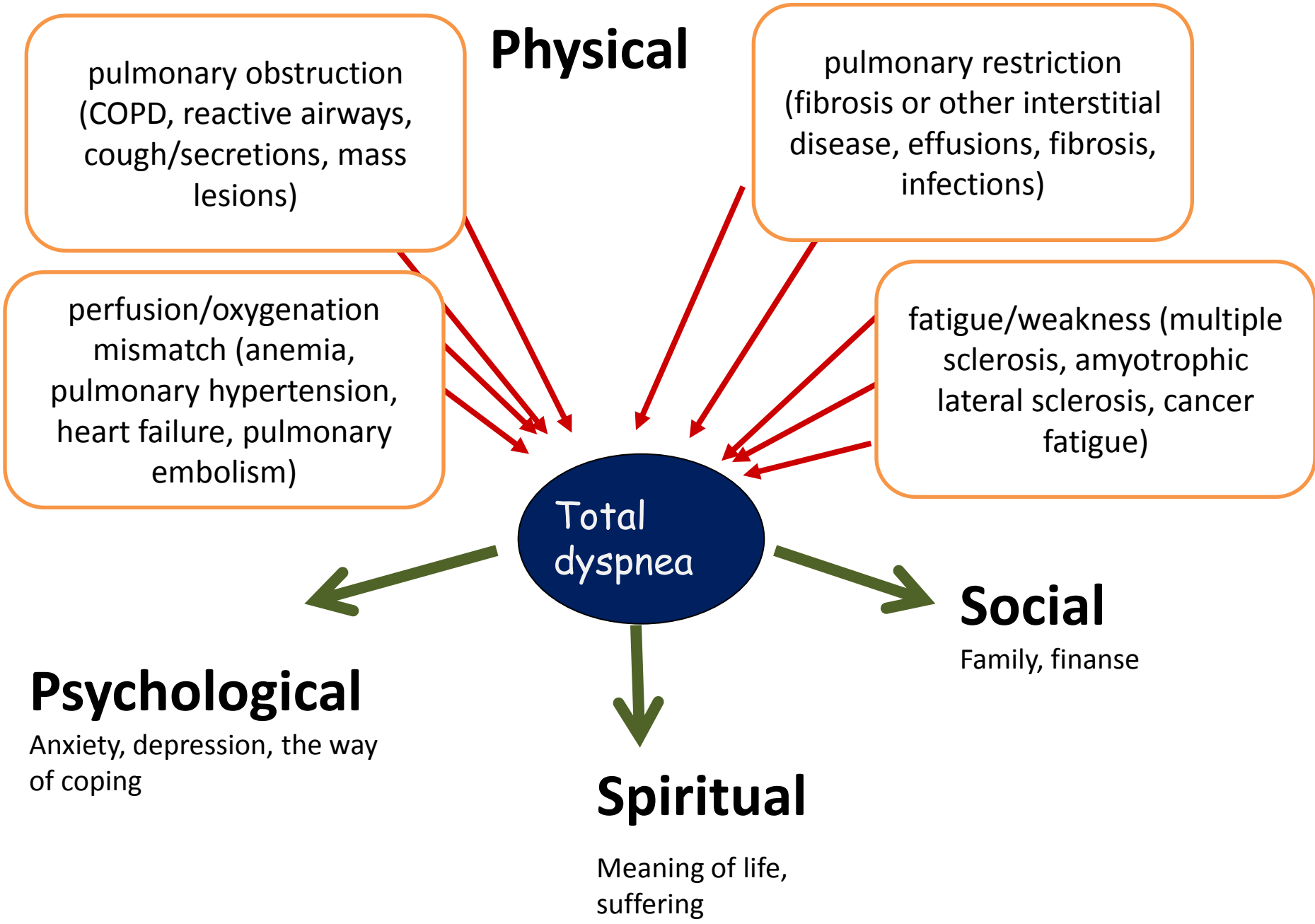
3. Total dyspnea

The presence of dyspnea at referral to PC was positively correlated with:

- severity of patient spiritual distress
- weakness
- low patient and family well-being,
- high staff anxiety
- a diagnosis of lung cancer
- and dying in hospital rather than hospice or nursing home

Edmonds et al. J Pain Symptom Manage 2000;19:15-22.

The concept of “total dyspnea,” - the complex etiology and manifestation of this symptom require multidisciplinary treatment plans that focus on psychological, social, and spiritual distress as well as physical components.


Physical
pulmonary obstruction (COPD, reactive airways, cough/secretions, mass lesions)
pulmonary restriction (fibrosis or other interstitial disease, effusions, fibrosis, infections)
perfusion/oxygenation mismatch (anemia, pulmonary hypertension, heart failure, pulmonary embolism)
fatigue/weakness (multiple sclerosis, amyotrophic lateral sclerosis, cancer fatigue)
Total dyspnea
Social
Family, finanse
Psychological
Anxiety, depression, the way of coping
Spiritual
Meaning of life, suffering

Kamal et al. J Palliat Med. Oct 2011; 14(10): 1167–1172.

Depression, sadness

Yearning (for peace, rest, forgiveness, etc)

Social issues (with family, community, etc)

Physical problems

Nonacceptance or spiritual distress

Economic or financial distress

Anxiety, anger

Total dyspnea describes the patient's experience of the symptom from multiple perspectives that, synergistically, combine to shape the symptom and to determine its impact

4. Assessment

Dyspnea:

- may occur at rest or with activity,
- may be continuous, intermittent or have a pattern of acute-on-chronic experiences
- effects those with and without primary cardiopulmonary disorders

4. Assessment

Identify causes

Describe (clinical characterization)

Beginning, other symptoms, „pattern" of episodes; physical activity (previous and present); anxiety (in relation to episodes); how carers react to episodes; what breathlessness means to the patients; impact of breathlessness on activity, social life etc; additional burden on family; what is effective; how drugs work; how the patient copes;

Subiective assessment

Intensity (NRS)

Unpleasentness (NRS)

Impact of breathlessness

Episodes

- N=70 pts with breatlessness in PC
- 39% - dyspnea at rest (but 20% at rest + episodic)
- 61% - dyspnea only as episodic

- Within the pts with episodic dyspnea:
  - 68% pts < 5 episodes/d
  - 88% episodes last < 10 min
- On average, breakthrough episodes occurred 5–6 times per day and lasted less than 5 minutes,
- Relation to fatigue, insomnia, anxiety, low well -being

Reddy et al. J Palliat Med. 2009;12(1): 29-36

4. Assessment

Identify causes

Describe (clinical characterization)

Beginning, other symptoms, „pattern" of episodes; physical activity (previous and present); anxiety (in relation to episodes); how carers react to episodes; what breathlessness means to the patients; impact of breathlessness on activity, social life etc; additional burden on family; what is effective; how drugs work; how the patient copes;

Subiective assessment

Intensity (NRS)

Unpleasentness (NRS)

Impact of breathlessness

Measurement of Dyspnea Intensity

- Standard single-item ordinal scales such as the visual analogue scale (VAS), numerical rating scale (NRS, e.g., 0 [no breathlessness] to 10 [worst possible breathlessness])

- Clinically, a straightforward standardized scale (e.g., 0–10 NRS) alone or as a part of a longer symptom list (e.g., ESAS) is likely best.

- As most dyspnea is intermittent, assessment involves questioning both the patient's current symptom burden and experiences over the last 24 hours.

SI (Sensory qualities)

- „Air hunger”: often in heart failure; chemoreceptor stimulation;
- „Sense of excessive work of breathing”: in muscle weakness or cachexia
- „Tightness”: often in bronchospasm; asthma;

Lansing R et al. Respiratory Physiology & Neurobiology 167 (2009) 53–60

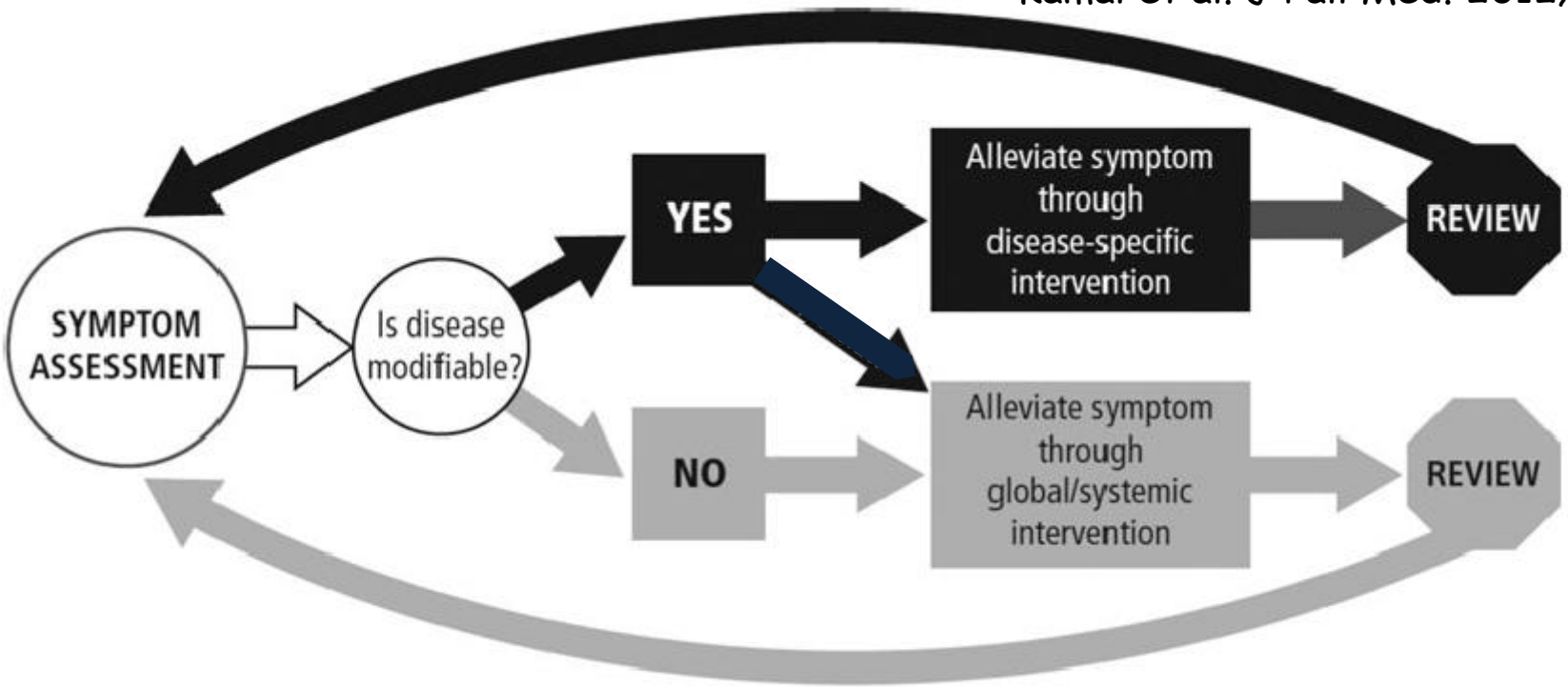
„Biopsychosociospiritual" model

dimention	Symptoms/signs	management
Physical		
Psychological		
Social		
Spiritual		

Campbell et al. Patients who are near death are frequently unable to self-report dyspnea. J Pall Med. 2009;12:881-884.

5. Management

Kamal et al. J Pall Med. 2012;



Biopsychosocial and spiritual model of management in dyspnea

Majority of pts with advanced cancer and dyspnea have at least 1 potentially reversible cause of dyspnea
[*Dudgeon et al. J Pain Symptom Manage 1998;16:212-9*]

Palliative management:

Directed on multiple mechanisms of dyspnea

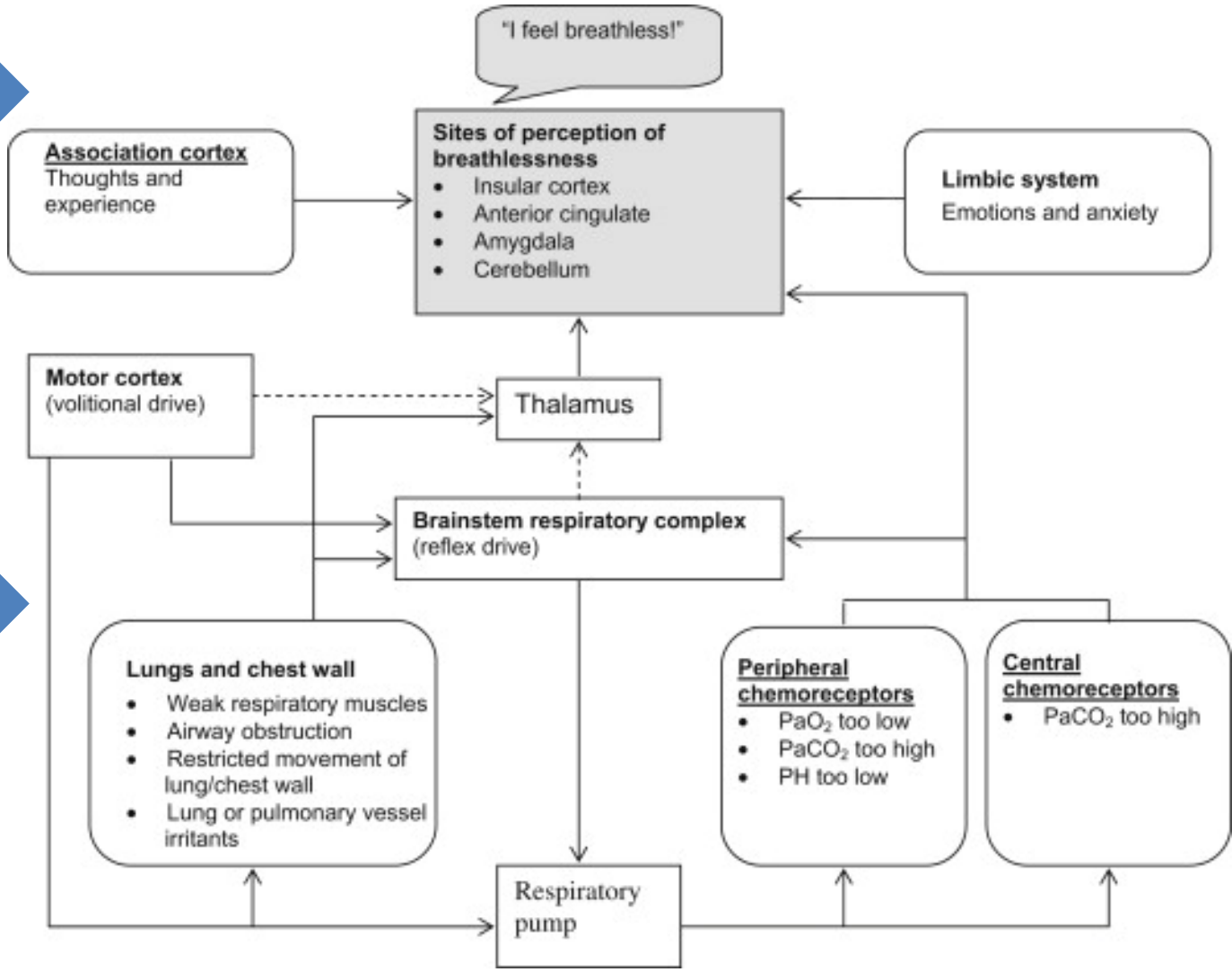
Impact on sensoric and motoric integration of cortical centers + impact on perception

Pharmacological + non-pharmacological interventions

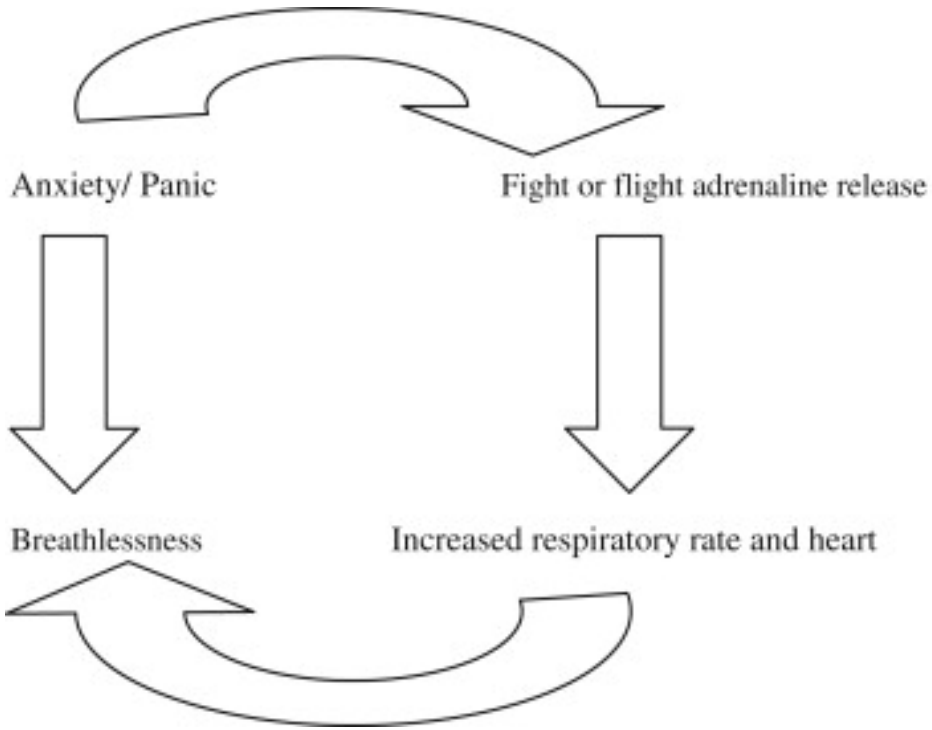
Action plan in case of episodic breathlessnes

Impact on perception

Impact on sensoric and motoric integration of cortical centers



Moosavi & Booth., 2011



Anxiety and panic both play an important role in the development of dyspnea and, in turn, are exacerbated by its presence—setting up a pernicious spiral of cause and symptoms;

Management – what has been proven in cancer patients

Non-pharmacological interventions and systemic opioids

Booth et al. Nonpharmacological interventions for breathlessness. Curr Opin Support Palliat Care 2011;5:77-86

- Proven non-pharmacologivcal interventions:
  - Flow of cold air directed to face by hand held fan
  - Walking aids
  - Neuromuscular electrical stimulation.
- Respiratory exercises, position, relaxation, support for carers, education – usually help indirectly

Pharmacological treatment

Systemic opioids in breathlessness – efficacy proven in RCT

Jennings et al. Opioids for the palliation of breathlessness in advanced disease and terminal illness.. Cochrane Database of Systematic Reviews 2001

Currow et al. Once-daily opioids for chronic dyspnea: a dose increment and pharmacovigilance study. J Pain Symptom Manage. 2011 Sep;42(3):388-99.

Central mechanisms:

Decreasing respiratory drive (↓ ventilatory response to hypercapnia, hipoxemia, and exercise, decreasing respiratory effort and breathlessnes); impact on rythm generation;
Improvements are seen at doses that *do not* cause respiratory depression.

Altering central perception (↓ *air hunger*)

Decreasing anxiety

Peripheral mechanisms:

Altering activity of peripheral opioid receptors (on PNECs nad C nerve fibres in bronchial epithelium; submucosal glands; macrophages and cancerous cells)

1. In opioid-naive – test dose of 2,5 mg (- 5 mg) p.o. morphine in immediate release preparation

2. Decision – depends on assessment of efficacy;
(if ≥ 2 doses/24h, start regular morphine (by titration)

3. Titrate the dose.

4. If stable controlled – consider rotation to controlled-release preparation + rescue doses

5. In „opioid-tolerant": depends on previous dose given for pain (f. ex.in mild dyspnea a dose equivalent to 25–50% of the q4h analgesic dose may suffice);

6. In COPD initial dose is 0.5 – 1 mg p.o.

7. In renal failure – modify dose or choose different opioid (hydromorphone)

8. In anxiety-dyspnea cycle – if non-pharmacological mamagement is not effective - anxiolytics

Problem of safety of opioids

Systemic opioid can relieve chronic refractory breathlessness [*Jennings et al. Cochrane Database of Systematic Reviews 2001.;*
Abernethy et al. BMJ 2003;327:523-528].

Titration up to 30 mg morphine daily might safely improve breathlessness in over 60% of patients with a mean decrease of 35% in the intensity of breathlessness from the persons own baseline
[Currow et al. J Pain Symptom Manage. 2011 Sep;42(3):388-99].

Lower dose opioids are not associated with increased risk of hospital admission or death in patients with respiratory failure associated with COPD *[Ekstrom et al. ….national prospective study. BMJ 2014]*

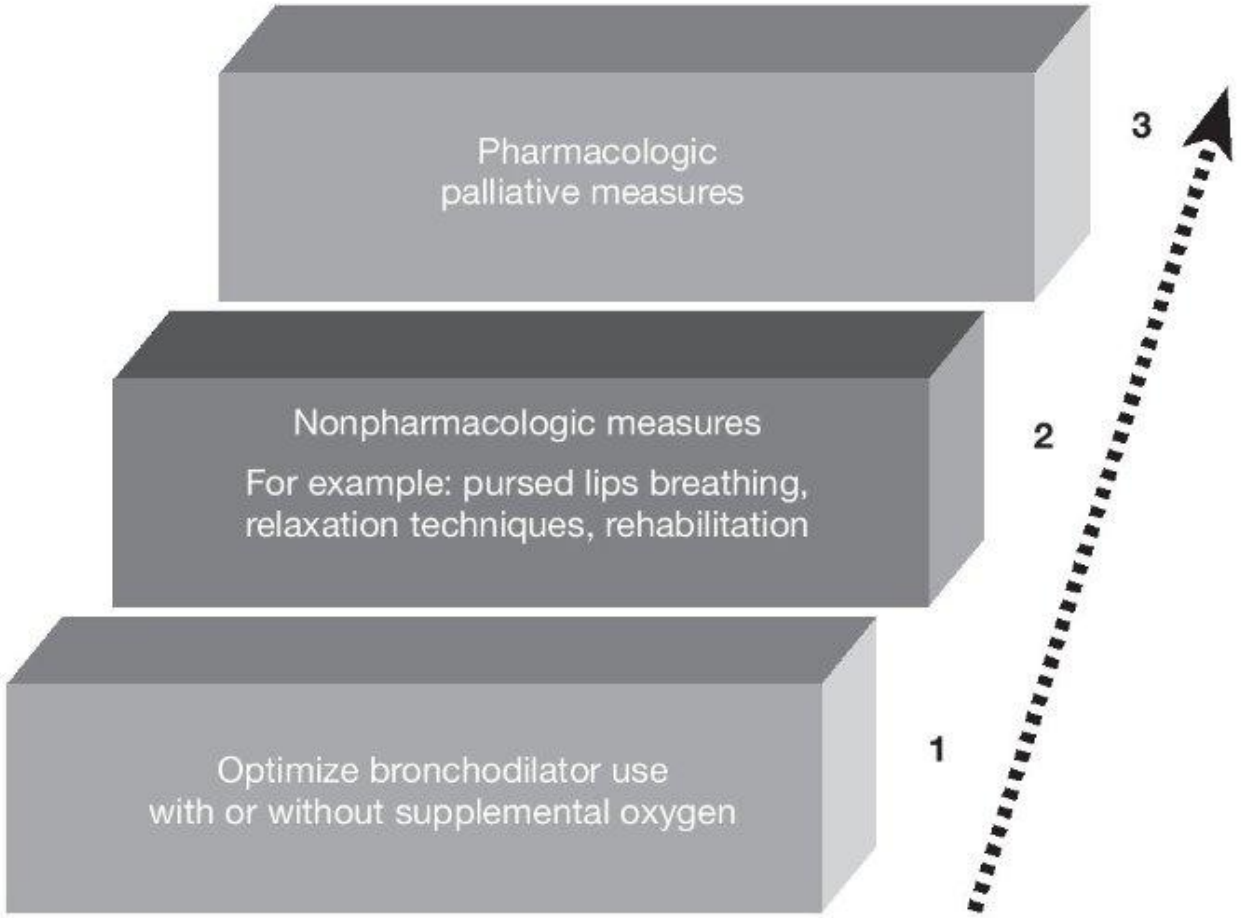
Mahler et al. American College of Chest Physicians Consensus Statement on the Management of Dyspnea in Patients With Advanced Lung or Heart Disease. *CHEST 2010; 137(3): 674 – 691*

***Pneumonol Alergol Pol* 2012;80(1):41-64.**

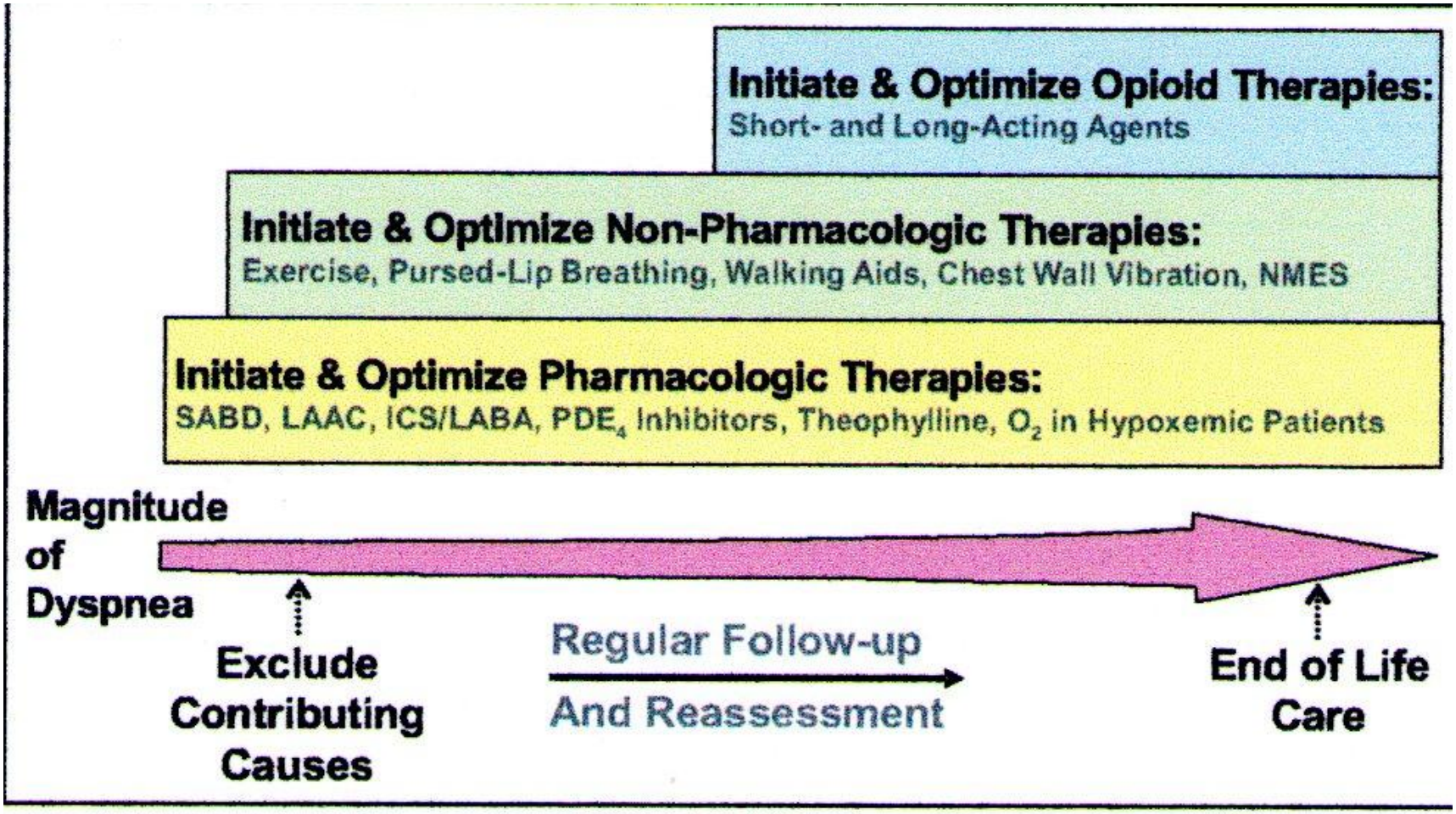
Zalecenia Polskiego Towarzystwa Chorób Płuc dotyczące opieki paliatywnej w przewlekłych chorobach płuc

Reccomendation of Polish Respiratory Society for palliative care in chronic lung diseases

Spanish Society of Pulmonology and Thoracic Surgery. Recommendations for End-of-Life Care in Patients With Chronic Obstructive Pulmonary Disease. *Arch Bronconeumol. 2009;45:297-303.*



Marciniuk et al. Managing dyspnea in patients with advanced COPD: a Canadian Thoracic Society clinical practice guideline. Can Respir J. **2011**;18(2):69-78.



Canadian Thoracic Society clinical practice guideline. Can Respir J. **2011**;18(2):69-78.

Suggested protocol for managing dyspnea with opioid therapy in advanced chronic obstructive pulmonary disease patients

- Initiate opioid therapy with oral immediate-release morphine syrup – titrate slowly at weekly intervals over a 4- to 6-week period
- Start therapy with morphine 0.5 mg orally twice daily for 2 days, and then increase to 0.5 mg orally every 4 h while awake for remainder of week 1
- If tolerated and indicated, increase to morphine 1.0 mg orally every 4 h while awake in week 2, increasing by 1.0 mg/week or 25% dosage increments/week until the lowest effective dose that appropriately manages the dyspnea is achieved
- Once a stable dosage is achieved (ie, no significant dose change for 2 weeks and dyspnea managed), a sustained-release preparation at a comparable daily dose could be considered for substitution
- If patients experience significant opioid-related side effects such as nausea or confusion, substitution of an equipotent dose of oral hydromorphine could be considered (1 mg hydromorphine = 5 mg morphine)
- Stool softeners and laxatives should be routinely offered to prevent opioid-associated constipation

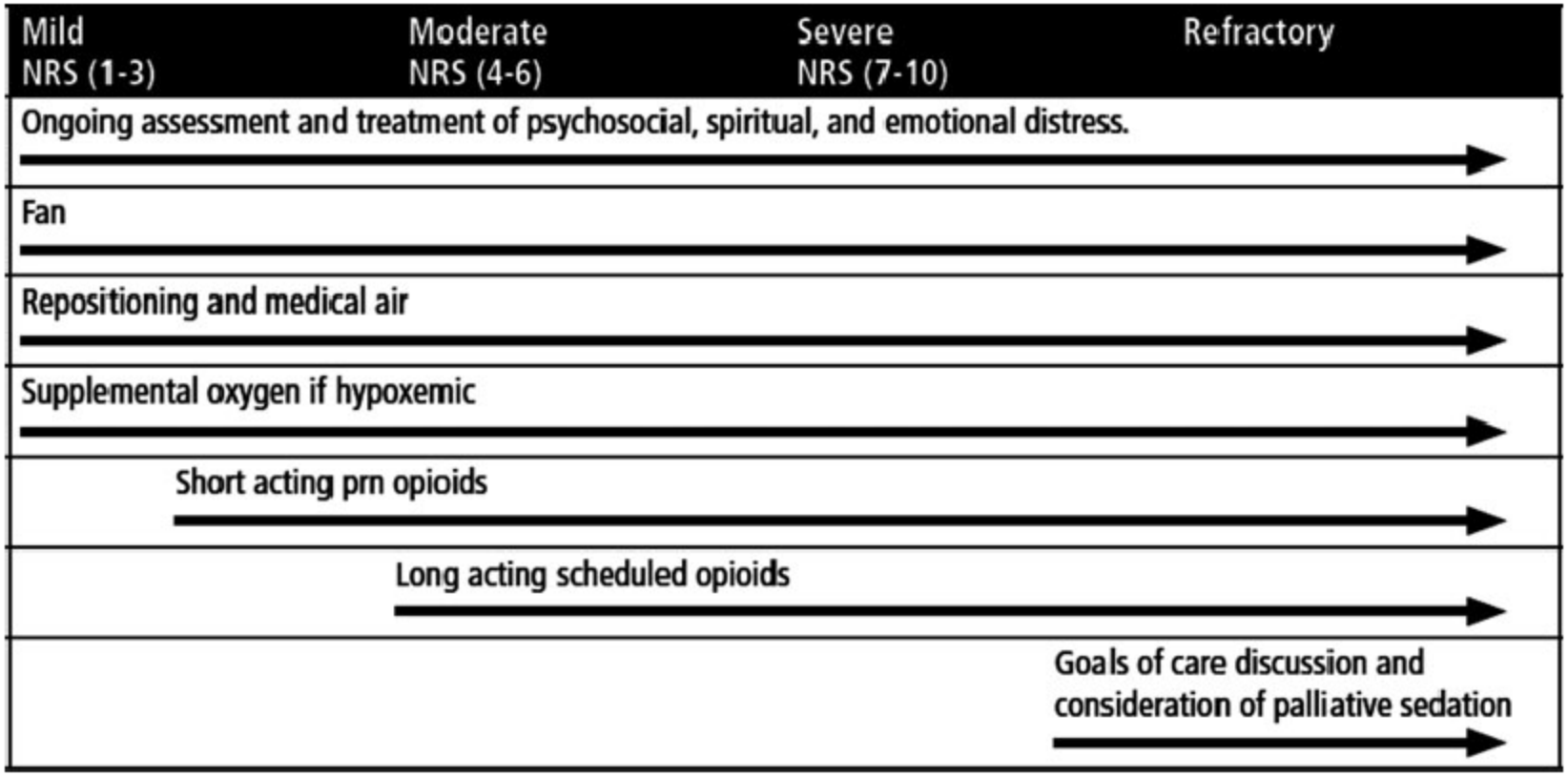
Other pharmacological treatment

- Benzodiazepines
- Other anxiolytics and antidepressants
- Oxygen
  - *Abernethy et al.. Lancet. 2010:376:784-93*
  - *(u osób bez hipoksemii – N of 1; jeśli tlen – to próba 3 dni)*
- Furosemide in nebulisation ?
- Cannabinoids ?
- Non-invasive ventilation (in cancer??)

Intervention	Agent	Conclusions
Medical Gas	Oxygen – Hypoxemic	↑
	Oxygen – Normoxemic	↔
	Medical air – Normoxemic	↔ or ↑
Pharmacologic	Opioids – oral/IV	↑
	Opioids - inhaled	↓
	Inahaled furosemide	↔
	Anxiolytics	↔
	Heliox	↔
Non-pharmacologic	Fan	↑
	Pulmonary rehabilitation (in select patients)	↑
Surgical	Pleural catheter	↑
	LVRS (in select patients)	↑
	Bronchial stenting (in select patients)	↑
Complementary	Acupuncture	↔ or ↑

↑ Evidence generally supports use of intervention
↓ Current evidence does not support use
↔ Further investigation required
↔ or ↑ Further investigation is required, but emerging data are compelling to support use

Kamal et al. JOURNAL OF PALLIATIVE MEDICINE 2012;



Kamal et al. JOURNAL OF PALLIATIVE MEDICINE
Volume 15, Number 1, 2012;

Ritual for crises

Action plan for Challenging Anxious Thoughts and Unpleasant Body Symptoms

- I have had this feeling before – I know it will go away soon.
- I am going to going to get into a position that I know helps me recover from breathlessness.
- I am going to use my fan and concentrate on breathing out.
- There is nothing to be frightened of – I really am ok.
- I can do this – I am doing it now.

(After you have recovered from feeling anxious or more breathless, remember to look back on the event and say 'I did it. Next time I will not have so much to worry about.')

The Cambridge BIS Manual, 2011

Shortness of breath action plan

If you get short of breath more than you normally experience, you can begin this action plan while you are calling your hospice nurse (if enrolled in hospice).

Nurse/hospice phone number: (999)-999-9999

1. Check oxygen connections to **make sure oxygen is working** correctly. Ensure the nasal cannula is positioned in your nose.
2. Make sure your room is **cool and use a fan** directed at your face to circulate air if you have one.
3. Create a **peaceful environment** using comforting music, dim lights, blankets, etc. Sit upright if you are able.
4. If it has been more than one hour since your last **breathing treatment,** you may **repeat** a breathing treatment of albuterol and ipratropium.
5. You may **take a dose of your medication** such as morphine concentrate 5mg or other pain med at this time to help with your shortness of breath.
6. If the above things have not helped in 30 minutes you may also now take a **dose of medication for anxiety** Lorazepam 1mg.
7. Remember again to **call your hospice nurse** if you have not already done this and are enrolled in hospice.
8. If the things above have still not helped significantly after 60 minutes then your may take another dose of morphine concentrate 5mg which can help with your shortness of breath.

If all of the above measures have not helped within 1–2 hours you may repeat all of the above in consultation with your hospice nurse (if enrolled in hospice).

Leigh & Tucker, 2013

Breathlessness Intervention Service (BIS)

Farquhar et al. Study Protocol: Phase III single-blinded fast-track pragmatic randomised controlled trial of a complex intervention for breathlessness in advanced disease. Trials. 2011;12:130.

CHEST CLINIC

The active identification and management of chronic refractory breathlessness is a human right

David C Currow,[1] Amy P Abernethy,[1,2] Danielle N Ko[3]

„Failure to enquire about, assess and properly treat chronic refractory breathlessness with opioids as outlined in specialist clinical guidelines is now substandard medical care and is also a breach of clinicians' ethical and legal duties to the patient".

Summary

Comprehensive assessment

Combining non-pharmacological and pharmacological methods

Opiods in refratory dyspnea also in non-malignant disease