Studying symptoms: challenges and new developments

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Overview

- Symptoms – terminology & history
- Symptoms – concepts
- Symptoms – assessment
- Symptoms - new developments
    - Symptom clusters
    - Computerized assessment

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Symptoms – terminology & history

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Definition and prevalences

- **Present definition**
  - ***"A symptom is a perception, feeling or belief about the state of our body"***
- **Symptoms common - in 443 persons followed for 10 years**:
  - 9.4 instances per year with symptoms at a level high enough to be described as illness!
- **Norwegian general population – cross-sectional data**
  - 22% fatigued above level for case definition
  - 11% chronic fatigued (above level for case definition for $\geq$ 6 months)
  - 17% poor appetite
  - 25% constipation
  - 32% dyspnoea
  - 46% pain at some level

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Symptoms – terminology & history

- **Greek origin – combining the roots for**
  - Piptein – to fall
  - Sym – together
  - ”Anything that has befallen one” – a fall from the usual state
- **Aristotle’s postulation:**
  - The heart as the center for sensations and emotions
- **Renaissance**
  - Shift from heart to brain as center for sensations
  - Pain as sensation perceived by the brain – still connected to the heart!
  - Mechanistic perception of nervous system (Descartes)

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The status of symptoms in medicine

- **When do symptoms constitute a disease?**
  - The symptoms-to-disease question
- **Rules or norms – differences through-out history**
- **Middle ages – late 19th century**
  - Symptoms (or signs) related to particular diseases
  - No clear distinction between symptoms and signs
- **Late 19th century**
  - Differentiation between symptoms (subjective) and signs (as observed by the physician)
  - Rooted in the fundamental medical discoveries – pathology/microbiology second part 19th century
  - Diseases more and more defined by signs than by symptoms
  - → Symptoms lost status – further supported by advances in medical technologies

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What is a symptom at present?
- pain as an example

- Pain is:

  An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage (IASP)
- Pain is always subjective (IASP)
- Inability to communicate verbally does not negate the possibility that an individual is experiencing pain (IASP)
- The definition avoids tying pain to the stimulus (IASP)
- Pain is always a psychological state, even though we may well appreciate that pain most often has a proximate physical cause (IASP)

➔ Symptoms are affected by culture, cognitions, emotional state and beliefs

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Types of symptoms

- **Physical symptoms**
  - A perception, feeling or belief about the state of the body
  - Physical symptoms are most commonly associated with pathological processes – pain from bone metastasis
- **Psychophysical symptoms**
  - Not clearly physical or psychological in origin
  - Commonly observed in psychosomatic conditions dominated by medically unexplained symptoms
- **Psychological / emotional symptoms**
  - Observed as self-reported mental states
  - Can be observed in psychiatric conditions
  - Fear, worrying, sadness….

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Symptoms – concepts

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Symptoms – simple or constructs?

- **Some symptoms – conceptually simple**
  - Single items may suffice for assessment
  - E.g "*Have you vomited? (not at all, a little, quite a bit, very much*)" on the EORTC QLQ-C30
- **Some "symptoms" – latent constructs**
  - Cannot be adequately measured by single items
  - An underlying construct, or "latent variable", that we tap into by asking the patient a number of separate questions
  - Constructs often multi-dimensional
  - Constructs = "useful fictions"
  - Latent variables are usually assessed by means of multi-item tests
  - Examples: Psychological phenomena, pain, fatigue….

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Pain – how many dimensions?

- **A systematic review on pain assessment tools** *(Holen et al 2006)*
- **80 instruments identified**
    - < 50% assessed pain as uni-dimensional
- **11 dimensions identified!**
- **> 1000 items on these dimensions!**
    - Most items on pain interference (>200)
- **6 palliative experts ranked importance of dimensions:**
    - Pain intensity, temporal pattern, treatment and exacerbating/relieving factors, pain location and pain interference on functions
    - No instrument covered all these 5 dimensions

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Fatigue – a symptom or being ill?

- **Different types – is fatigue = fatigue?**
  - Eg.: Is fatigue in depression = fatigue in cachexia?
  - Mental, physical..
- **Multi-dimensional phenomenon? How many dimensions?**
  - Physical aspects
  - Emotional aspects
  - Cognitive aspects
  - Behavioural aspects ……
- **Physical fatigue – included in all definitions**
  - Feeling of lack of energy – most relevant in palliative care?

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Fatigue cont.

- **Symptoms - not a direct expression of disease**
  - Neuronal pathways for some symptoms - nausea
  - No specific pathways identified for fatigue – a final common end point?
- **Fatigue has low specificity**
  - Fatigue characteristics similar in mental and somatic disorders
  - Analogy to blood pressure – the pressure does not differentiate between causes
- **”Fatigued” behavior in other mammals**
  - Fatigue: Inseparable from the illness experience? The illness?

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Fatigue cont.

- **Accompanies most diseases**
  - The most prevalent ”symptom” in cancer patients?
- **Several potential underlying mechanisms**
  - None fully explains fatigue
- **Fatigue a complex construct**
  - Definition, measurement, types
  - Not a simple symptom
  - Several measurement systems available – but few comparisons
- **Fatigue = sickness behaviour**
  - Part of the experience of being seriously ill

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Symptoms – assessment

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EAPC – expert group recommendation

- **Lack of consensus on pain measurement hinders meta-analyses**
  - Thereby hinders selection of optimal treatment in the clinic
- **NRS for simple assessment of changes in pain intensity**
  - Numerical rating scale (0 – 10)
  - VAS a misnomer
- **BPI-short form for multidimensional pain assessment**
  - In adult patients without cognitive impairment
  - BPI-sf 3 dimensions (severity: 4 items, interference with activity: 3 items; interference with mood: 4 items)
  - Is interference valid? Pain vs. other effectors upon functioning
- **Short Form McGill Pain Questionnaire**
  - Recommended for studies that specifically assess pain quality

Caraceni et al; J Pain Symt Manage 2002

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Fatigue: measurement by self-report

- **Single items (VAS, NRC, WRC)**
  - Wording decisive – feeling tired vs. exhausted
  - Not recommended
- **Uni-dimensional measures – measure physical fatigue**
  - HRQOL-instruments (EORTC / SF-36 / Fact F/A)
  - Not documented need for disease-specific measures
- **Multi – dimensional measures (no. dimensions)**
  - Fatigue Questionnaire (2)
  - Multidimensional Fatigue Inventory (MFI-20) (5)
  - ++++

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ESAS: Edmonton Symptom Assessment System

Capital Health

CARITAS HEALTH GROUP

Edmonton Symptom Assessment System:
Numerical Scale
Regional Palliative Care Program

Please circle the number that best describes:

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
Not tired	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
Not nauseated	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
Not depressed	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
Not anxious	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Not drowsy	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
Best appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible appetite
Best feeling of wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst possible feeling of wellbeing
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
Other problem	0	1	2	3	4	5	6	7	8	9	10	

Patient's Name _____

Date _____ Time _____

Complete by *(check one)*
- ☐ Patient
- ☐ Caregiver
- ☐ Caregiver assisted

BODY DIAGRAM ON REVERSE SIDE

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ESAS – some comments

- **Not fully validated**
- **Some prevalent symptoms not included**
- **A mixture of simple and complex symptoms**
  - Pain = pain intensity, not location or fluctuation!
  - Anxiousness = ? Worrying? Fear? Panic?
  - Depressed – screening *"Are you depressed?"*
- **≥ 3 cut-off for need for interventions – valid?**
- **Useful for screening and monitoring?**
  - Must be supplemented in most cases
  - By other assessment tools or by interviews
  - Most useful for screening and targeted interviews?

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New developments

- Symptom clusters
- Computerized assessment

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Symptom clusters

- **Symptoms neglected in medical research**
  - Regained interest in medically unexplained conditions
  - Symptom clusters become prominent in nursing cancer research
- **Co-existence of symptoms – a common observation**
  - Pain & depression
  - Dyspnoea & anxiety
  - Fatigue & poor appetite
  - ……
- **Concept of clustering of symptoms developed in**
  - **Psychology & psychiatry**
  - **Eg. psychiatric diagnostic systems**

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DSMIV- criteria for depression
= symptom clustering!

Criteria [1]	Type of symptom
1. Lowered mood [2]	*Psychological*
2. Anhedonia *²	***Psychological (?)***
3. Anorexia / weight loss	*Somatic*
4. Insomnia / hypersomnia	*Somatic*
5. Agitation / retardation	*Somatic*
6. Fatigue	*Somatic*
7. Feeling of guilt	*Psychological*
8. Lowered concentration	*Psychological*
9. Recurrent thoughts of death / suicide	*Psychological*

[1]: 5 or more criteria present for last 14 days and a change from previous functioning
[2]: One must be present
*: Anhedonia = lacking ability to feel pleasure of stimuli that usually gives pleasure

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Fatigue - different clustering:
Palliative patients vs. healthy controls

(Stone et al., 1999)

	Patients	Controls
Age	.00	-.08
Grip strength	-.16	-.08
HADS-A	.16	.40*
HADS-D	.18	.44*
Pain	.45*	.30*
Dyspnoea	.50*	.23*
Insomnia	.41*	.27*

* : $p < .05$

underlined : predictors in multivariate regressions

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What can be achieved by looking at symptom clusters?

- **Lessons learned from 30 years in psychiatry / psychology**
  - Relationships between symptoms
  - Relationships between symptoms and clusters
  - Relationships between clusters
  - Identification of underlying constructs
  - Identification of underlying etiologies
- **Lessons learned in general medicine**
  - Associations between symptoms, signs and diagnoses
- **Different statistical methods**
  - Correlations, factor analyses, SEM..

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What can be achieved by looking at symptom clusters in palliative care? cont.

- **Palliative patients - multiple symptoms simultaneously (>3, 11?)**
  - Identification of symptom patterns – underlying mechanisms
  - Which are mediated by the cancer itself – cytokines?
- **Pain, depression and fatigue**
  - Commonly co-occur
  - In which patterns?
  - Which fatigued patients are depressed?
  - Which fatigued patients are not depressed but develop cachexia?
- **Limitations**
  - No common definition on symptom clusters
  - Complicated methodology (assessment techniques and statistical analyses)
  - Palliative patients – symptoms fluctuate over time – instable patterns?
  - No proven clinical usefulness of the concept at present

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Symptom assessment by portable PC's

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Conclusions

- **Symptoms are not direct expressions of diseases**
  - **Affected upon by culture, cognitions, beliefs and emotional state – they are in the brain**
- **Some symptoms are simple**
  - An can be assessed by simple questions
- **Some symptoms are multi-dimensional constructs**
  - **Number and content of dimensions not agreed upon**
- **Symptom clustering - a new development in symptom research**
  - Can be of use to identify clinical conditions
- **Symptom assessment by computerized tools – the future?**
  - Can more easily help to identify clusters in the clinic?

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