Challenges and solutions to the diagnosis and treatment of psychological distress

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Very ambitious title for a 20 minutes speech at the end of a 2-days conference!

-Distress no diagnosis
-Title reflects the challenge?

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The main challenge

- Palliative Care: "…. *assessment and treatment of pain and other problems, physical, psychosocial and spiritual….."*
- The CSA-study – cross-sectional data
  - 17 cites, N=1000
  - 14% suffered from major depression
  - 24% of these on anti-depressants – 76% not
    - Anti-depressants are effective *(Rayner L 2010)*
  - 13% on anti-depressants - 73% not depressed – cured?
- A generic problem in modern medicine
  - Physicians neglect spiritual and psychological aspects *(Agledahl KM , JME 2011)*

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Outline

- Main focus for speech:

"Is distress a solution or a new challenge?"

- General issues
  - Terminology
  - Classification of psychological phenomena
- Stress and distress
  - Some general aspects
- Measurement of distress
  - In relation to cancer and palliative care
- Treatment
  - Some comments

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Slide 1

h1 hloge; 28.04.2009

General issues:

- Terminology
- Classification

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Psychological distress - terminology

- Complicated and often poorly defined term
  - Inconsistent use
  - Different meanings
  - Different subtypes
  - Not followed by specific actions – opposed to a diagnosis
    - Like other terms - Quality of life

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Psychological distress–terminology 2

- Different types of distress *(Wikepedia)*
  - Fetal distress
  - Respiratory distress
  - Emotional distress
  - Psychological distress
  - Suffering
  - ……..

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NCCN Guidelines (1998-2008)

- Chose the term distress because:
  - Acceptable and not stigmatizing
  - Sounds normal
  - Can be defined and measured by self-report
- NCCN defined distress as:

Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.

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Main challenge: Doctors ignore spiritual and psychological suffering

- *- "main failing of patient-doctor encounters is not a lack of courteous manners, but the moral offence patients experience when existential concerns are ignored……. Acknowledging this moral offence would, however, be the first step towards minimizing the effects thereof"* *(Agledahl KM 2011)*
- Does introducing the term distress improve on this?
  - I.e. do we achieve what the inventors want?
  - To improve detection and treatment of suffering by introducing the term distress?

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Tradition for avoiding psychiatric terms – anti-psychiatry

- General society - skepticism – shame
- Prof. skepticism
  - Physicians outsource psycho-social-existential
  - I.e. outsource the patient – not conditions
- Professional skepticism – QOL-movement
  - QOL – HRQOL: Aimed to be positively oriented
  - Therefore invented / used concepts

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Tradition for avoiding psychiatric terms – anti-psychiatry 2

- QOL-movement invented / used concepts for political reasons
  - QLQ C30: Emotional functioning
    - Do we function emotionally?
    - By 4 items, 2 on anxiety, 2 on depression
    - Not functioning – the scale measures symptom levels
    - I.e. distress
  - SF-36: Mental health! By 5 items
    - More ambitious than the title of this presentation
    - 3 items on depression – 2 on anxiety

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Use of the term distress – screening

- 2 recent reviews on distress instruments
  - Vodermaier A, J Natl Canc Inst 2009
    - **Ability to accurately detect adjustment, depression and anxiety disorders**
    - Ultrashort 1-4 items, N=9
    - Short 5-20 items, N=15
    - Long 21-50 items, N=9
  - Thekkumpurath P, J Pain Sympt Mange 2008
    - **Aim: Ability to detect depression**
    - 10 uni- and multi-dimensional scales

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Use of the term distress – 2

- The concept used more broadly, i.e. includes delirium
  - Kelly, Pall Med 2006
  - NCCN 2008
- Distinguish between emotional and psychological distress?
  - Emotions most commonly assessed
- 20% of surveyed US institutions screened for distress
  - Time for validating the NCCN-Guidelines including the term distress?
  - Easier to write than to implement guidelines

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Principles of psych. classification

- Man-made – not God-made (C. von Linné)
- Purpose of psychiatric classifications
  - Communication – between professionals
  - Control – i.e. select candidates who probably will benefit treatment
  - Understanding – quality control & research
- Most psych. symptoms occur in many conditions
  - Also in normal reactions such as depr. mood in sadness
- Some central criteria for counting as disorders:
  - Symptom constellation
  - Symptom load – how much of each symptom - i.e. intensity
  - Duration
  - Functional consequences

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Principles of psych. class. II

- DSM & ICD - non-hierarchical systems
  - Jaspers 1913 created a hierarchical diagnostic system: organic / schizophrenia / mood disorder / neurosis
  - The upper excluded the lower
- DSM & ICD - non-aetiological systems
  - Based upon symptoms & behaviors
  - Exception to non-aetiological: PTSD - a specific cause
- Psych. diagnosis = certain constellation of symptoms
  - i.e. symptom clustering
  - The diagnoses = the clusters

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Stress and distress

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Distress – the concept

- Stress – hard to define & hard to research
  - As many perceptions as people?
  - Never reached an agreed-upon definition
- In physics – leading to strain – old term
  - Form of the Middle English *destresse*, derived via old French from the Latin *stringere* – to draw tight *(Wikepedia)*
  - When English departed from the Nordic languages

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Distress – the concept II

- H Selye 1930's – introduced new terms
  - Stress - a "psychophysiological concept"
  - Stressor = the perceived threat
  - Stress - the reactions of the organism to external events
  - Renewed interest 1970's
- Distress – introduced by H Selye 1975
  - Eustress – the good stress - coping functions
  - Distress - persistent stress - not resolved through coping or adaptation
  - May lead to **anxiety** or withdrawal (=**depression**) behaviors
  - Failure to deal with stress - different from the NCCN definition

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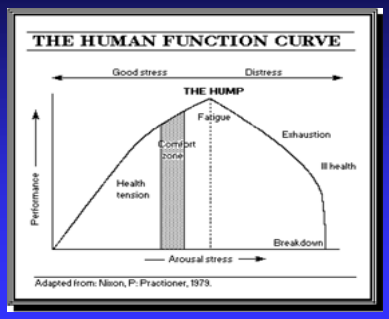
Distress – the original model



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Measurement of distress

-Not a diagnosis
-In relation to cancer and palliative care

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Measurement - general aspects

- Purpose of measurement – clinical / research
  - Screening/ diagnostic / treatment evaluation
- Types of measurement tools
  - Unidimensional / multidimensional
  - Multidimensional instruments can:
    - Assess several dimensions of one construct
    - i.e. pain intensity, interference… = domain-specific
    - Or assess different constructs by several scales

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Measurement - general aspects - 2

- Same challenge for all patient-reported measures
  - EPCRC-findings: No. of available instruments increases!
  - Many only used once – by the inventors
- Quality of instruments
  - User-friendliness
  - Measurement capabilities (validity/reliability)
    - i.e. how does the instrument function in each particular population

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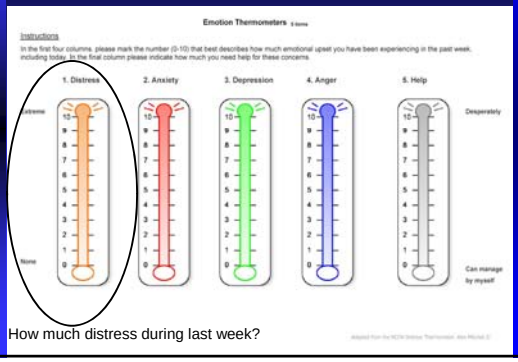
Distress in pall./cancer care - the Distress Thermometer



How much distress during last week?

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The Distress Thermometer II

Additional content:

- Indicate problematic areas the past week (Yes / No)
- Practical problems (5 items)
- Family problems (2 items)
- Emotional problems (6 items)
- Spiritual / religious concerns
- Physical problems (21 items)
  - Bodily functioning
  - Mobility
  - Different symptoms
- Familiar with content ?
  - As multidimensional HRQOL-instruments
  - I.e. – distress replaces QOL

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The Distress Thermometer III

- Published 1998 – in relation to NCCN guidelines
- "*The benchmark for measuring the distress level of patients with cancer*" (*JC Holland 2001*)
  - It is an assessment method – to be compared to others
- Validated for evaluation of distress
  - And anxiety and depression
  - Cut-off was 4v5 – revised in 2007: 3v4
  - Rationale?
- Introduced as a screening tool
  - Psychometric properties for psychiatric case detection: 50%
  - Compared to other screening tools?
  - Further developed into Emotion Thermometers

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A proposed solution - distress and depression - NCCN

- ***"NCCN guidelines (2008)"*** - algorithm
- Brief screening tool – risk score
- Assessment of risk factors
- > 4 - referral to
  - Mental health, social or pastoral services
- Evaluation for
  - Dementia
  - Delirium
  - Mood disorder - **depression**
  - Adjustment disorder
  - Anxiety disorder
  - Substance-related or personality disorder

NCCN Guidelines 2008, www.nccn.org

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Distress: the assessment model

Screening → Psychiatric disorders
- Depression, delirium, anxiety...

Screening → Distress → Psychiatric disorders
- Depression, delirium, anxiety...

- Traditional screening vs. NCCN guideline model
  - Which model is optimal?

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Distress & depression – some comments

- Does depression cause distress or is depression extreme distress? - NCCN
- Distress = poor HRQOL
  - From content of the Distress thermometer
  - Suffering better term? – good face validity
- Worth considering
  - Does avoiding the psycho-term reduce stigma?
  - Does a new term improve practice?
    - An empirical question
    - Does it help in identifying treatable conditionsdisorders?

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Proposal – short and dirty

- For assessment of emotional distress
  - ESAS or similar for screening or clinical purposes
    - Physicians - look at the scores
    - Interview the patients if positive scores
  - In research – relate to purpose
    - Use an instrument that assesses anxiety and depression
    - With best possible psychometrics given available space
    - EF - QLQ C30, MH SF-36 – unidimensional instruments with good psychometric properties
    - Multi-dimensional domain-specific instruments if purpose
    - PHQ-9 assesses the 9 DSM-criteria for depression – can reduce to 5 items?? CSA-data indicate this

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Treatment

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Treatment – challenges & solutions

- Main challenge – under-detection of treatable conditions (depression, anxiety, delirium)
  - Of psychosocial aspects in general
  - How to improve clinical practice? Doctors' practice?
- Improve physicians' communication competence?
  - Physicians not willing to change communication based upon research findings *(Oken 1961, Novack 1978)*
  - Physicians still regard communication as personal *(Rogg L 2010)*
- More research – of any help?
- Optimal solution – political?
  - Inform the Norwegian public on CSA-findings?

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Treatment – challenges & solutions 2

- Minor challenges
  - Lack data on effects of specific treatment regimens
    - Anxiety – 1 RCT
    - Depression – 4 RCTs
    - Adjustment disorders – 0 RCTs?

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Treatment – challenges & solutions 3

- *Minor challenges cont.*
  - Lack data on comparison between treatment alternatives
    - Psychological treatment vs. antidepressants
      - EPCRC Depression Guideline – strengths of evidences vary
  - Diagnostic entities do not fit the pall. population?
    - Depression, adjustment disorders, demoralization
  - Natural courses - not known
  - Optimal solution – more research

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Conclusions

- Distress
  - Introduced for political reasons
- Measurement in rel. to purpose
  - NCCN Guidelines recommend unidimensional assessment
  - Vast number of instruments – none superior
- Treatment
  - Under-detection - **the significant problem**
  - Underlying psychiatric condition not treated
    - Delirium, depression & adjustment disorder
- What improves care, treatment and research?
  - A broad concept like distress?
  - Or focus on defined and treatable conditions?
  - I.e. depression, delirium & adjustment disorders

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