



MEETING REPORT

COMPASS Research Collaborative Strand 1 Masterclass, March 2008 Assessment and measurement of psychological distress in supportive and palliative care

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Background:

There is currently great variation in the assessment and measurement of psychological distress in palliative care. Strand 1 of the COMPASS collaborative represents a programme of work that is examining the appropriateness of different assessment tools, taking into account patient preference and stage of illness assessed, with the aim of developing core standardized measures. At a meeting in London, researchers discussed current thinking on measurement of distress in palliative care. The specific aims were:

- 1) *To debate instruments for assessment of distress in supportive and palliative care intervention trials; their use to define cohorts and as outcome measures*
- 2) *To explore the possibilities for developing shared data sets to inform selection of instruments in such trials*

The meeting included a series of presentations followed by open discussion.

Attending:

- Irene Higginson: *Head of Department of Palliative Care, Policy and Rehabilitation, Honorary Consultant, King's College Hospital, London*
- Dan Stark: *Senior Lecturer & Honorary Consultant, University of Leeds*
- Mike Bennett: *Consultant and Professor of Palliative Medicine, Lancaster University and St John's Hospice, Lancaster*
- Peter Speck: *Senior Researcher, Kings College London/Southampton*
- Matthew Hotopf: *Professor of General Hospital Psychiatry, Institute of Psychiatry, London*

- Alex Mitchell: *Consultant in Liaison Psychiatry, Leicester General Hospital*
- Gao Wei: *Medical Statistician, King's College Hospital, London*
- Kate Hill: *COMPASS Post-doctoral Research Fellow, University of Leeds*
- Sue Hall: *Lecturer in Palliative Care, King's College Hospital, London*
- Bee Wee: *Visiting Research Fellow, King's College Hospital, London*
- Annet Kleiboer: *COMPASS Post-doctoral Research Fellow, University of Edinburgh*
- Jonathon Koffman: *Lecturer in palliative care, MSc Course Co-ordinator, King's College Hospital, London*
- Farida Malik: *Cicely Saunders International Research Training Fellow, King's College Hospital, London*
- Lauren Rayner: *Research Associate, King's College Hospital, London*

Presentations:

INTRODUCTION TO STRAND 1 WORK AND LINKS WITH EPCRC

Professor Irene Higginson, Head of the Department of Palliative Care, Policy and Rehabilitation at Kings College London

The COMPASS Collaborative encompasses three main strands of work – assessment, interventions and implementation. Strand 1 is concerned with assessment and outcome measurement.

- *Why is assessment so important?*
- Appropriate assessment is essential if patients are to receive effective treatments at the right time
- A core set of appropriate outcome measures is required for 1) the evidence base 2) meta-analysis
- Measures used for assessment are often repeated to give an assessment of change – i.e outcome measurement
- *Why is there so much variation in estimates of the prevalence of depression?*
- Wide range of screening tools
- Debate over whether depression is a 'symptom' or a 'syndrome'
- Questionable suitability of some tools for use among people with advanced disease (symptoms, looking to the future)
- No consensus on which assessment tool to use, when and in whom
- This has limited meta-analysis on the treatment and prevalence of depression
- *Strand 1: five year research aims*
- To agree a standardised core set of assessment and outcome measures
- To determine the best core measures for different stages of illness
- To determine ways to shorten measures and minimise the burden placed on patients by using psychometric methods
- To develop efficient ways of monitoring patients' symptoms and well-being both at hospital and at home
- *Three components of research to determine core measures*
- Reviewing and consensus – systematic review addressing conceptual and practical issues and psychometric properties, Delphi consensus exercise among clinicians and users
- Longitudinal study – exploring practical issues and psychometrics over time, use of proxies, shift response

- Analytical – use data-sets to examine shortened scales, single items, relationship between scales, handling missing items
- *Challenges to be addressed*
- Variation in concepts
- Variation in measures
- Validity at different stages of illness – problem of somatic symptoms, practical concerns, response shift
- Use of technology – e.g. phones, touch screens
- *EPCRC – European Palliative Care Research Collaborative*
- Aim - to develop methods for the assessment, classification and management of pain, fatigue and depression.
- Work on assessment and classification of depression led by Jon Harvard Loge, based in Norway. Systematic review of 200 studies on assessment of depression. 95 different assessment measures used, huge variation by time and place
- Work on development of guideline for treatment of depression led by Irene Higginson, based in London

OPTIMAL ASSESSMENT OF PATIENTS

Professor Matthew Hotopf, Professor of General Hospital Psychiatry at the Institute of Psychiatry, London

- Tension exists between 'ideal' and 'pragmatic' practice
- Psychiatric diagnosis is not clear-cut – even 'gold standard' measures such as DSM-IV can seem arbitrary (why does bereavement preclude a diagnosis of depression, but not other traumatic life events such as divorce?)
- Diagnosis is a description not an explanation
- Where do we draw the line between ordinary feelings and mental disorder (e.g shyness and social phobia, sadness and depression)?
- Arguably, the point of diagnosing is to identify people likely to be helped by treatments. Thresholds where illness is diagnosed could be defined in terms of response to treatment
- Assessment measures vary:
- Screening measures to detect a 'case' focus on threshold – usually a short self-complete questionnaire e.g HADS
- Assessment scales such as the HDRS and BDI describe severity and detect change during treatment. The BDI prioritises cognitive symptoms, the HDRS gives greater weight to sleep and anxiety
- Measures vary but are not that much...
- Hotopf (1998) compared four psychiatric scales (CIS-R, HDRS, BDI, GHQ-12) and found that 80% of variance was explained by a single factor "depression"
- All measures are flawed – but it is better to use old (flawed) measures than new (flawed) measures

Discussion

- What is the relationship between depression and psychological distress? Is distress a component of depression, or is depression a clinical manifestation of distress?
- Should we be focusing on reducing the symptoms of the most severely depressed, or on reducing symptoms in the entire spectrum of distressed people

NEW DEVELOPMENTS IN RAPID SCREENING FOR DISTRESS

Alex Mitchell, Consultant in Liaison Psychiatry, Leicester General Hospital

- 'Depression' is a communication tool – diagnosis gives permission to prescribe treatments
- The HADS is currently the most commonly used screening tool
- *What is the purpose of screening?* Detection rates, unassisted rates, subsyndromal disorders
- Subsyndromal depression is more common than either minor or major depression and includes a significant number of patients with appreciable distress and anxiety. Patients with minor and subsyndromal depression may be at risk of deterioration
- *Current detection methods* - unassisted accuracy, screening habits, what are the optimal questions?
- *Test duration:* 1) ultra-short screening tools (1-4 items, taking less than 2 minutes to complete). 2) short screening tools (5-14 items, taking between 2 and 5 minutes to complete). 3) standard screening tools (15 or more items, taking more than 5 minutes to complete)
- *The Distress Thermometer* – patients are asked to circle the number (0-10) that best describes how much distress they have been experiencing in the past week. Also asked to circle causes of their distress, listed under the following categories: practical problems, family problems, emotional problems, spiritual/ religious concerns and physical problems
- *The Emotional Thermometer* – patients are asked to circle the number (0-10) that best describes how much emotion upset they have been experiencing in the following categories: distress, anxiety, depression, anger. Patients are also asked to indicate how much help they need for these concerns (0-10)
- *Emotional Thermometer vs. Distress Thermometer* - Of 130 patients, 37% scored above the cut-off recommended by the NCCN on the Distress Thermometer versus 69% on the Emotional Thermometer. Of the 63% of Distress Thermometer low scorers, 51% recorded emotional difficulties on the new Emotional Thermometer

Discussion

- What is the nature of the distress we are measuring? What do the questions mean to the individual being assessed? Be aware of language and cultural differences
- Are depression and distress perceived differently.
- What help should be offered to patients who are identified as distressed/ depressed
- What is the prognostic significance of diagnosis? Does diagnosis influence what happens next?

THE ASSESSMENT OF EMOTIONAL DISTRESS IN CANCER: A SYSTEMATIC REVIEW OR THE LITERATURE

Dr Kate Hill, Research Fellow, COMPASS Supportive and Palliative Care Research Collaborative, Department of Oncology, Leeds

- MeSH and Tree searches for key concepts
 - Distress, emotional distress, psychological distress, spiritual distress
 - Cancer, neoplasms, tumour, palliative care
 - Assessment, measurement
- Total hits 26,637 – Exclusions 15,844 – Inclusions 2080
- *Categories for inclusion*
 - Distress: Studies assessing emotional and psychological distress 1488
 - Existential: Studies assessing hope, meaning and spirituality 255
 - Gold Standard: Studies using a standard clinical interview assessment 94
 - Psychometrics: Papers reporting developmental or validation studies 177
 - Reviews: The identification, classification and assessment of distress 66
- *Research Questions*
 - How do measures inter-relate?
 - Timing of assessments?
 - Different stages of illness?
 - Different clinical settings?
 - Symptom clusters?
 - Measuring outcomes?
 - Response shift?
 - Patient preferences?

Discussion

- Need to prioritise what to do with this data
- Stage of illness is important – distress relating to the diagnosis of disease is different to distress relating to living with advanced disease. Early diagnosis and treatment distress Vs. existential distress at the end of life
- NICE recommend regular assessment at various stages covering: pre-diagnosis, diagnosis, treatment, remission, survival, end-of-life
- Look at longitudinal data (though in the minority and heterogeneous)
- Do they provide a map of distress throughout the cancer journey?
- Which measures work best in longitudinal studies?
- Are any psychometric measures validated in longitudinal settings?
- How do we decide which accuracy/ validation level is acceptable?
- What is the 'gold standard' for change?
- What evidence is there that it is helpful to screen for distress?
- Minor depression is a risk for major depression – is distress also?
- Are there economic implications? Life expectancy of a 'case' on the HADS is greater than a 'non-case' - opens doors to palliative care services and raises healthcare costs
- Need to consider anxiety - often the biggest problem for patients and difficult for clinicians to manage. Distress maps better onto anxiety than depression.
- Research priorities 1) longitudinal analyses 2) impact of distress

DEVELOPING AGREED CORE MEASURES AND CONSENSUS

Dr Dan Stark, Senior Lecturer in Cancer Medicine, Honorary Consultant in Medical Oncology, Leeds

- *Existing work:*

- Joan Teno's annotated bibliography of instruments to measure quality of care at end of life
- Classified and recommended instruments using psychometrics, conceptual basis, language issues, patient burden
- *Item-based analysis, item banks and the PDI*
- Item-based models describe latent traits (such as psychological distress) and redundant items
- They rely upon uni-dimensionality – i.e that the single latent trait accounts for all the variance in the data
- Where the dataset fits the model, they can independently estimate: where a person falls along a continuum (level of trait); where an individual item falls along the same continuum (item location)
- *NIH PROMIS (USA):*
- Set up to address: 1) diversity of measures 2) response to change 3) burden 4) validation
- Method: build item pools and develop (Item Response Theory) core questionnaires that measure key health outcome domains that are manifested in a variety of chronic illness
- Advantage: encompasses all measures – collaborative, not 'owned'
- Problem: different populations have different latent traits; not interested in palliative care, limited interest in emotional distress
- *COMPASS Consensus/ Delphi:*
- Aim: develop core set of standardised patient-led assessment and outcome measures
- Method: consensus, including user involvement and experts
- Scope: Type of measure: assessment, outcome
- Patient groups: points in cancer journey, clinical setting
- Definition of 'best': psychometrics, service user and academic preference, minimising burden
- Advantages: Wider range of experience – may reduce impact of error
Consider range of old and new options
A group may be more influential than an individual
- Disadvantages: Decision making is difficult – domination, cost, dissent
Can be difficult to control discussion and keep on track
- Approach to cues/ content: Tighter cues allow larger numbers of cues to be considered systematically to improve reliability?
- Type of measure: assessment – characteristics of patients when entering studies
Outcome: change in symptoms either side of an intervention
- Point in illness journey: around diagnosis, during initial treatment, at home after initial treatment, at relapse, in terminal phase?
- Clinical setting: home, hospice, hospital?
- Panel Members: All important stakeholders from the population we seek to influence – service consumers, health professionals working in the area, managers and policy makers
- What will we use to define 'best' measures?
- Reliability (internal and test-retest)
- Validity: construct, content, concurrent
- Responsiveness to change
- Subgroups
- Service user and expert preference
- Minimizing burden

Discussion

- Knowing endpoint will help us define the Delphi process
- Aim: to get people using the same measures
 - : achieve consensus about which measures are best for screening and assessing change/ severity
- Is this aim achievable?
- What are we trying to get out of the Delphi exercise? What would be the most helpful outcome?
- Funders are dubious when there is lack of consensus on measures
- Review and Delphi to work in tandem
- Delphi will identify which questions we explore in the data

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