

The routine use of patient reported outcome measures in health care settings: a guide for clinicians



Jill Dawson (Senior Research Scientist),
Department of Public Health,
University of Oxford &
Visiting Professor,
Oxford Brookes University.

Main points to be covered

- **My area of expertise**
- **PROMs – Introduction**
- **Choice of instrument**
- **Process: data collection and storage**
- **Examples of uses and possible abuses**
- **Recommendations**

- **My expertise**

PROMs summary

- **Questionnaires - systematically measure patients' subjective health status** (symptoms, function, QoL).
- **Generally designed for use in clinical trials** – eg. to compare outcomes of different Rx groups.
- **Increasingly used for other purposes.**

PROMs – a special type of questionnaire

- **Questionnaires designed to measure a particular phenomenon or construct.**
- **Vary in degree of specificity**
 - eg. Generic (SF-36, EQ-5D)
 - Condition/site-specific (AIMs, EORTC questionnaires)
- **Represent the patient's perspective.**

PROMs – a special type of questionnaire

- **Questionnaire designed to measure a particular phenomenon or construct.**
 - Individual items scored to produce a scale(s).
 - Has to be justified: measurement properties.

PROMs - Measurement properties

- **Acceptable to patients** (completion rates)
- **Reliable** (reproducible)
- **Valid**
- **Responsive** (Sensitive to change)

PROMs - Measurement properties

- **Precision**

- **Rasch analysis** (item response theory)

- Underlying scale structure dimensionality, hierarchy and interval location of items (patterns of items' difficulty or severity).
 - Requires specialist software and expertise.

PROMs' proliferation

- from review Garratt et al. *BMJ* 2002

Problems

- Numerous measures of variable quality
- Selecting appropriate PROMs difficult
- Recommendations not straightforward

PROMs - Choosing a PROM

- **Measurement properties of an outcomes questionnaire not *of the questionnaire alone*.**
 - Depend on the context and sample characteristics.
 - If these change, so *may* the measurement properties.

PROMs - Choosing a PROM

- **Read through the questions!**
 - Note period of recall.
 - Consider gender, age-group, intervention.
 - Also consider timing of follow-up (in relation to the questions).

PROMs - Process

1999

Mars orbiter – costing \$125 million - lost by NASA because one engineering team used metric units while another used imperial units for a key spacecraft operation.

PROMs - Process

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- **Process requires careful planning and organisation.**

PROMs - Process

- **Outcome measures preferably used to measure **change**.**

= data collection at least 2 points in time.

The same points in time - for everyone - relative to the intervention.

PROMs - Process

- **Regularise data collection system.**
- **Involve and train staff** (eg. dates).
- **Data storage.**
- **Pilot everything.**

Outcome measures – uses and abuses

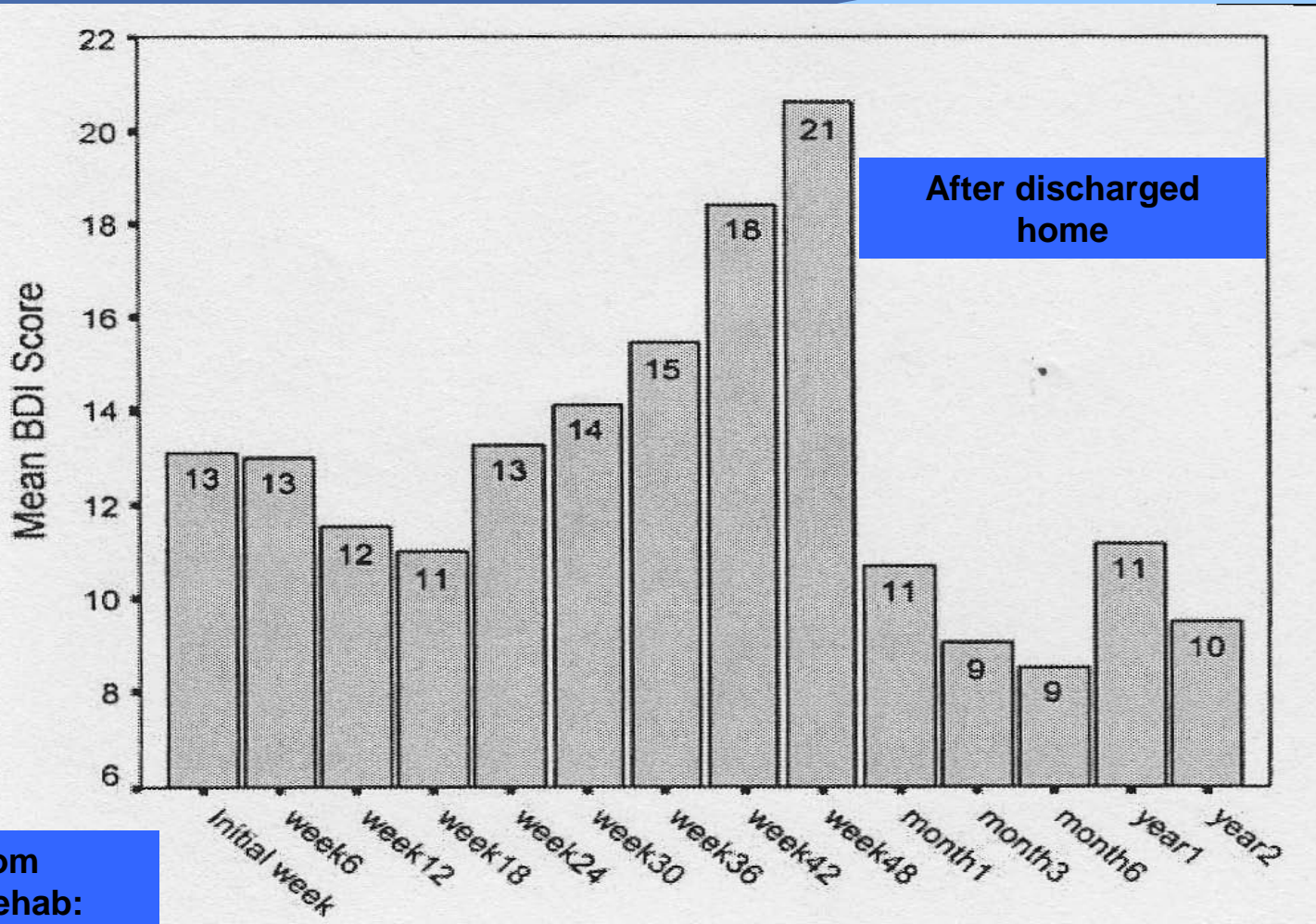
1) **Appropriate measure poor process**

- **Little/no thought about future analysis or ‘research question’ &/or**
- **Little thought about process.**
 - ➔ **Outcomes collected in non-systematic fashion.**

An example.....

Example: Study of Anxiety and depression after spinal cord injury (n=104 patients)

Beck depression inventory – Interviews /postal after discharge

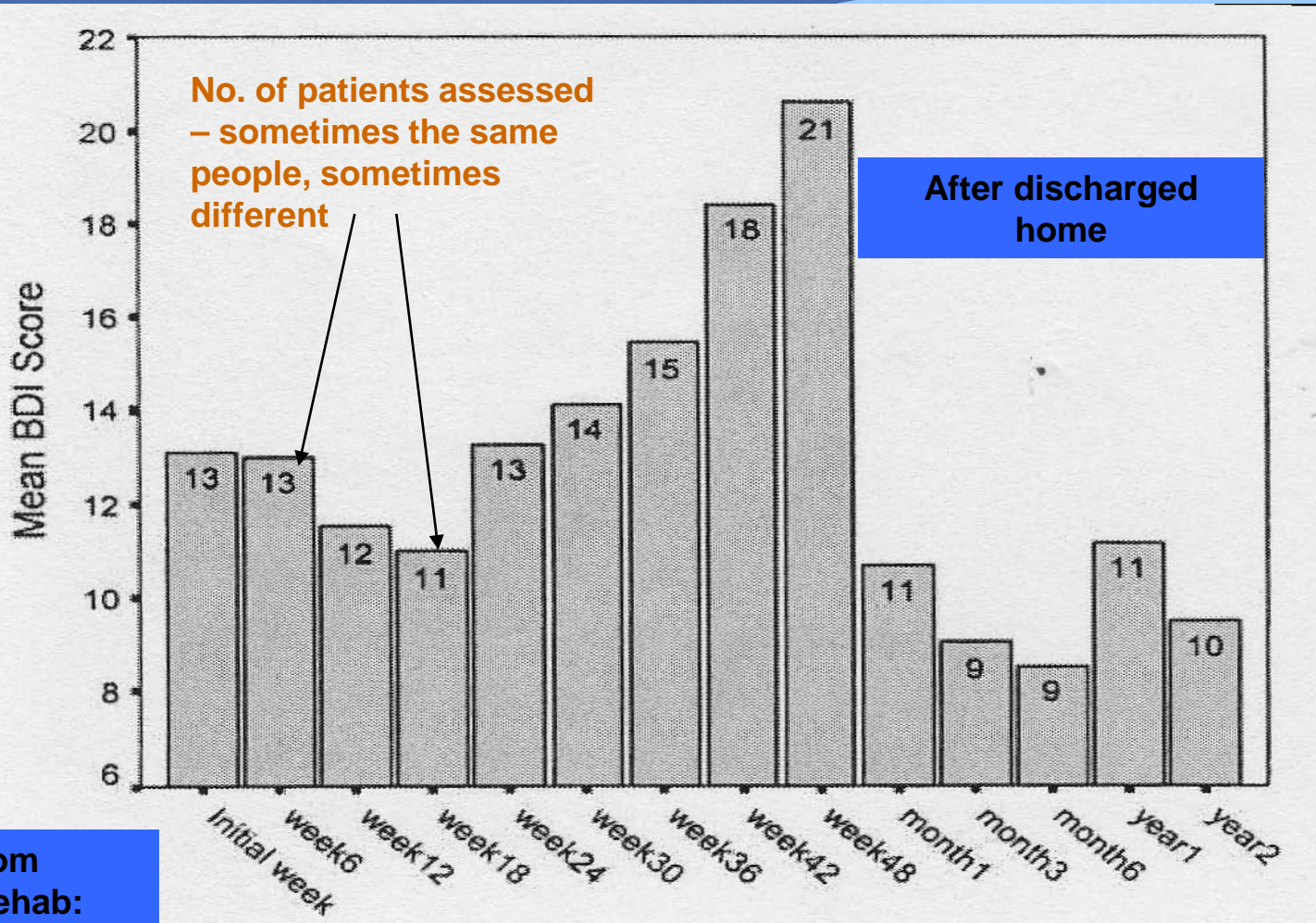


No. of weeks from admission for rehab:

Conclusion: the longer pts stay in hospital the more depressed and anxious they become.

Example: Study of Anxiety and depression after spinal cord injury (n=104 patients)

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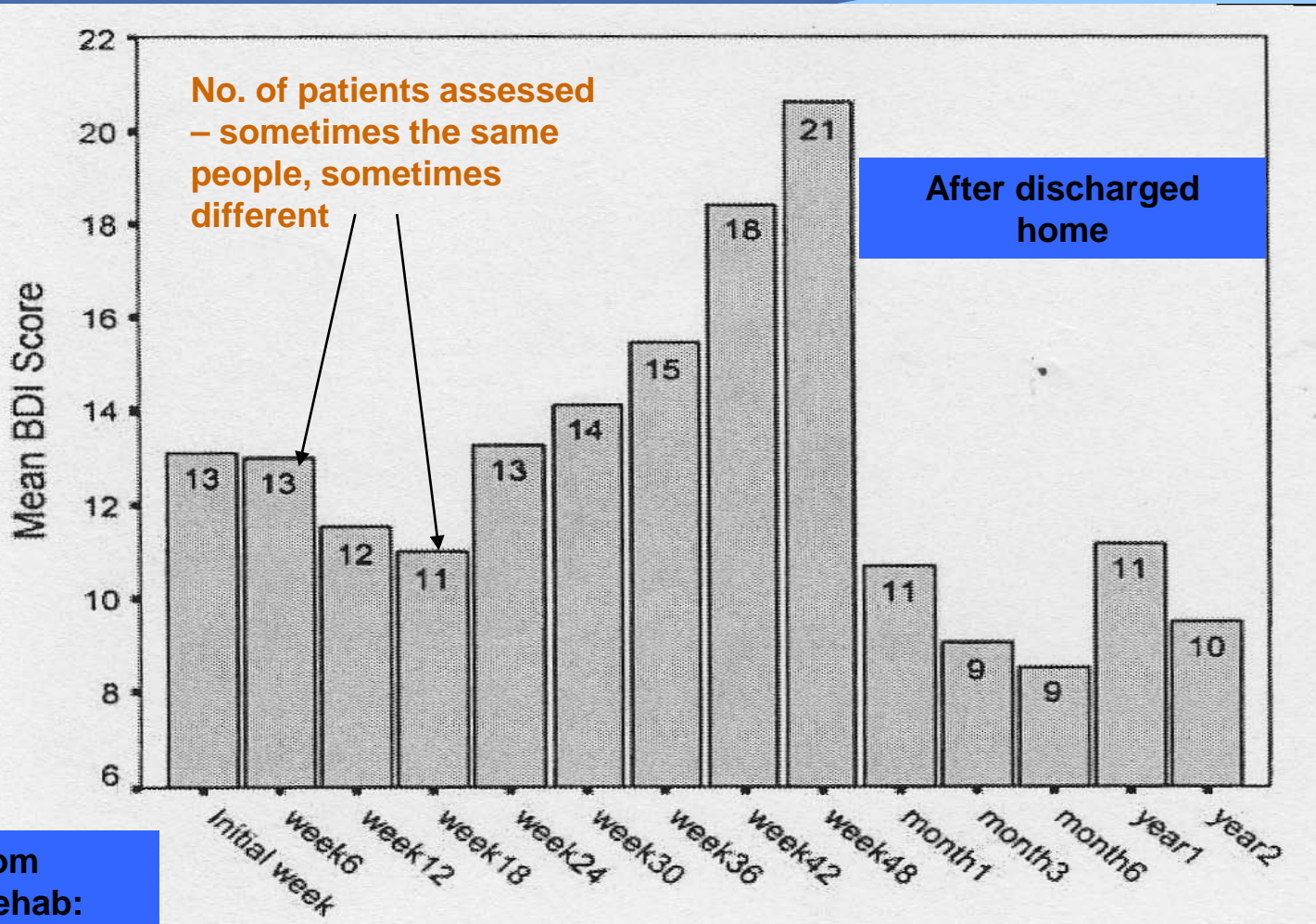


No. of weeks from admission for rehab:

Conclusion:

Example: Study of Anxiety and depression after spinal cord injury (n=104 patients)

Beck depression inventory – Interviews /postal after discharge



Conclusion: Likely very biased data - can't be represented as a trend – no other conclusion.

Outcome measures – uses and abuses

2) Loss of standardisation: changing a validated measure.

- **The wording of a ‘validated’ instrument should not be changed.**
- an example...

Outcome measures – uses and abuses

2) Loss of standardisation: changing a validated measure.

Example: Figure from a recently reviewed paper:
‘The Oxford knee score’ (item - as used in this study)

Outcome measures – uses and abuses

2) Loss of standardisation: changing a validated measure.

Incorrect wording of Oxford Knee Score item:

5. How painful has it been to stand up from a chair because of your knee?

- | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| No pain | Slight pain | Moderate pain | Severe pain | Unbearable |

Outcome measures – uses and abuses

2) Loss of standardisation: changing a validated measure.

Correct wording of Oxford Knee Score item:

During the past 4 weeks.....

5. **After a meal sat at a table**, how painful has it been **for you** to stand up from a chair because of your knee?

**Not
at all painful**

**Slightly
painful**

**Moderately
painful**

**Very
painful**

Unbearable

Outcome measures – uses and abuses

3) Assessing and screening individuals

- **Validated patient-reported measures generally designed for group comparisons.**
 - **Not usually designed (or reliable enough) to assess and screen individuals.**
 - **Cut-off points.**

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- **Select most appropriate measure for intended purpose and population.**
- **Check for evidence of satisfactory measurement properties.**
- **Plan data collection like a military exercise.**

Finally.....

"To consult the statistician after an experiment is finished is often merely to ask him to conduct a post-mortem examination. He can perhaps say what the experiment died of."

R.A. Fisher
1938

- **Seek advice from the start.**