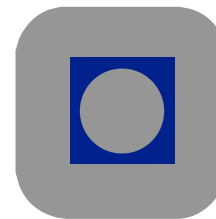


Implicit Comparisons and other Response Shifts

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What is response shift?

- **Examples:**

- Patient appears stable, but reports changing HRQoL.
- Patients may appear to be deteriorating, yet report unchanged HRQoL.
- **Extreme case: The Disability paradox:**
 - *“Why do many people with serious and persistent disabilities report that they experience a good or excellent quality of life when to most external observers these individuals seem to live an undesirable daily existence?”*

(Albrecht & Devlieger)



Adaptation to illness

- **Clinical approach:**
 - **With chronic diseases, a major part of the management is helping the patient adapt or cope – which leads to “response shift.”**



More examples of response shift?

- **Examples:**
 - **Contrary to the expectations of doctors or others, “patients appear to regard a minute chance of possible benefit as worthwhile, whatever the cost” and willingly tolerate horrendously toxic cancer therapy for little improvement in chance of survival.**

(Slevin, 1990).
 - **Patients may report less toxicity if they perceive a treatment to be working.**
 - **But, conversely: "there is no gain without pain" and for many patients the more a treatment hurts the more effective it is presumed to be.**

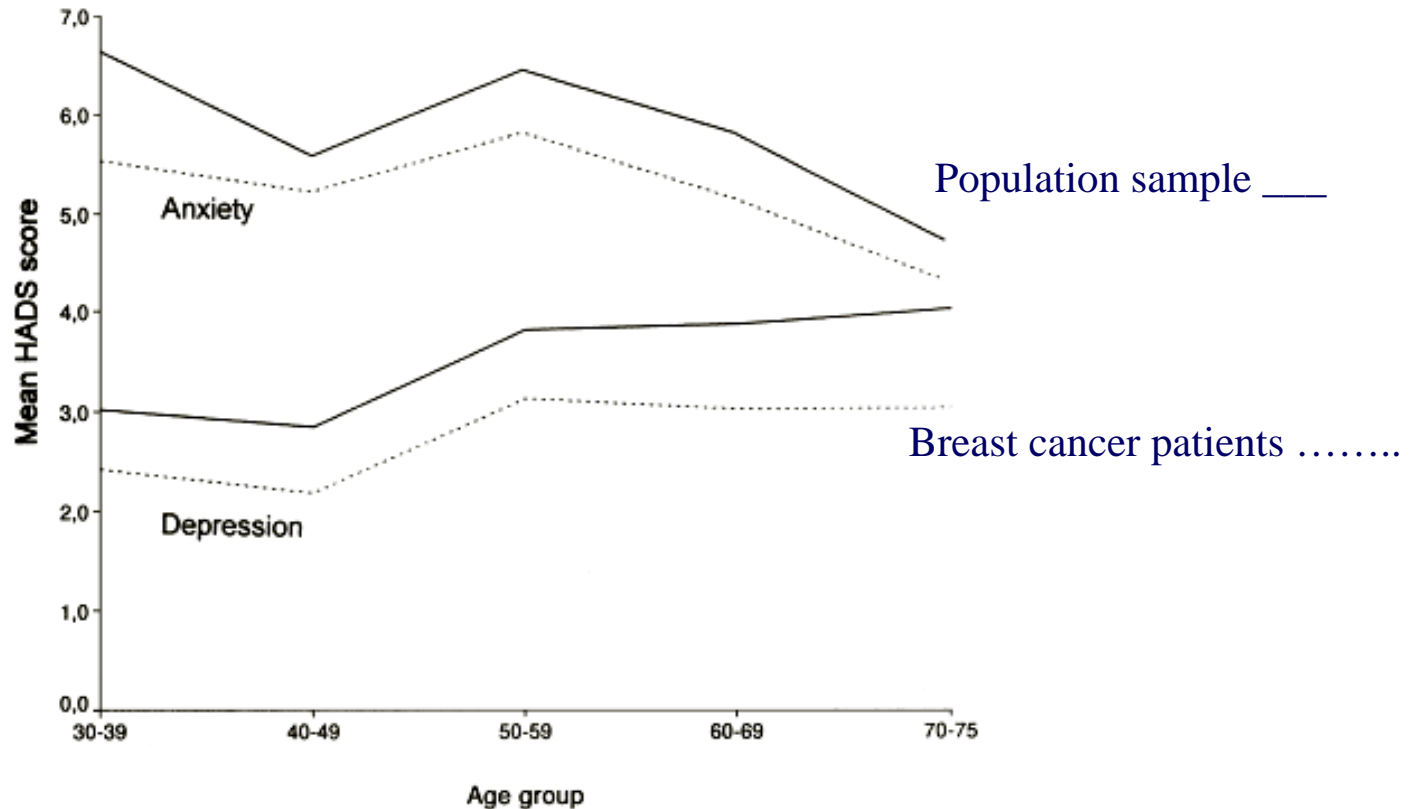


Low-risk breast cancer patients

- **Breast cancer patients from DBCG trials.**
 - **Low risk of recurrence.**
 - **N=466.**



Low-risk breast cancer patients



Groenvold, Fayers *et al.* (2000) *J Clin Epi* **52**: 523–530



Patients' perspectives

- **“During therapy I became more tired. At the start (before treatment), I may have thought I was tired, but now I say No, I was not tired at all. *Now I am* tired.”**
- **69 patients interviewed regarding fatigue.**
- **14 indicated response shift.**
- **11 of these thought, with the benefit of hindsight, that they had overstated their fatigue.**
- **The majority considered their revised responses to be more valid.** (Sprangers et al., 1999)
- **“Now I *really* understand the meaning of severe pain.”**



Response shift

- An elegant umbrella term that covers a range of otherwise “strange” and disparate phenomena
- “Adaptation to changing health – Response shift in quality of life research” Schwartz & Sprangers
- It indisputably happens to patients (and observers / carers?)
- Can it affect the interpretation of results clinical trials and other studies?



Definition

- **A change in the meaning of one's self-evaluation of a target construct, as a result of:**
 - a) A change in the respondent's internal standards of measurement (Scale "recalibration")**
 - b) A change in the respondent's values ("Reprioritisation")**
 - c) A change in the respondent's definition of the construct ("Reconceptualisation")**



Nothing is new

“What constitutes happiness is a matter of dispute

Very often the same man says different things at different times: when he falls sick he thinks health is happiness, when he is poor, wealth”

Aristotle, ~350 BC



Mechanisms for response shift

- **Examples:**

- **Coping**
- **Adaptation to illness**
- **Reframing expectations**
 - *Positive – Hope*
 - *Negative – “You have to face up to reality”*
- **Goal reordering**
- **Spiritual practice**

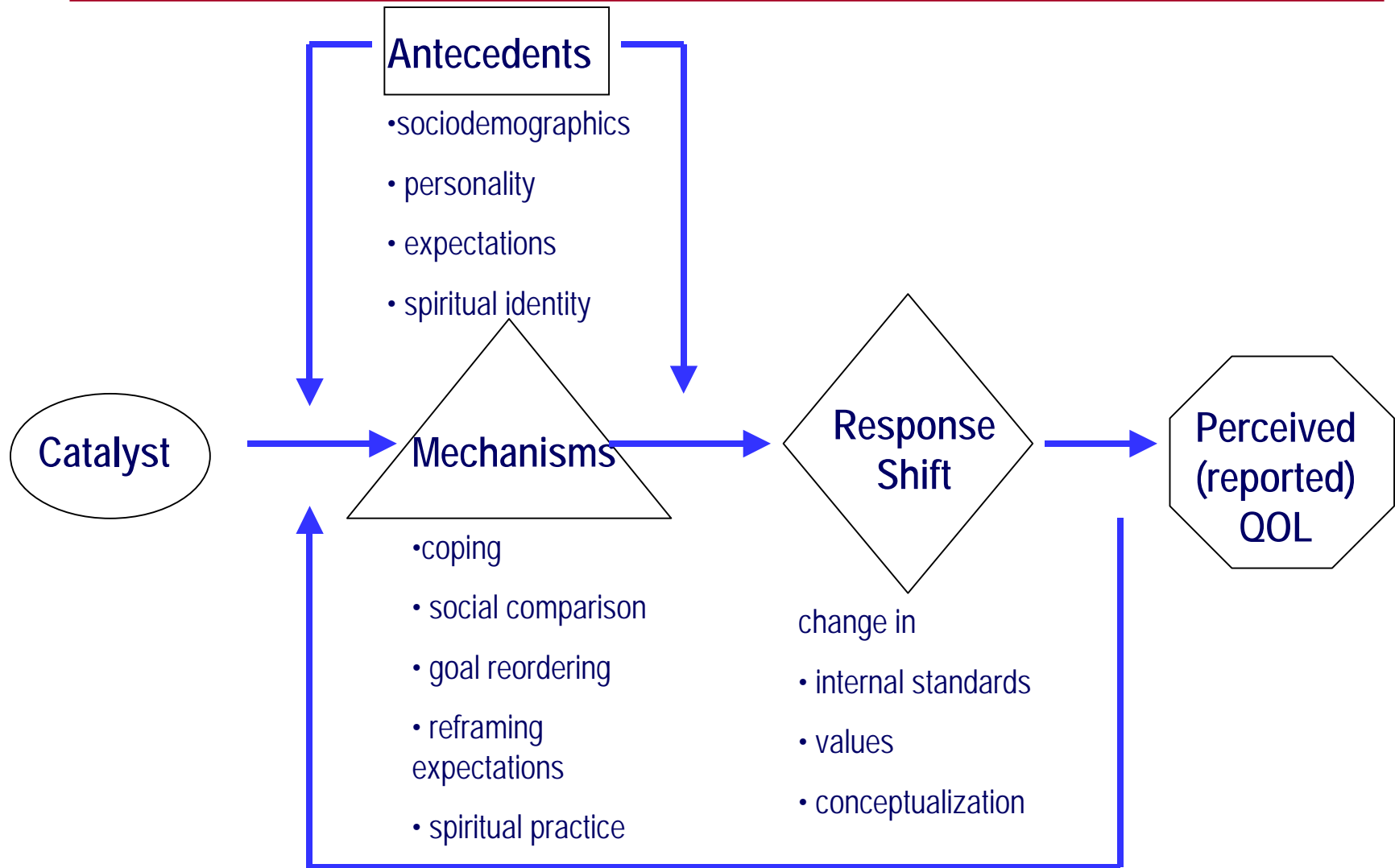


Processes of response shift

- **Recalibration**
- **Reprioritisation**
- **Reconceptualisation**



Model

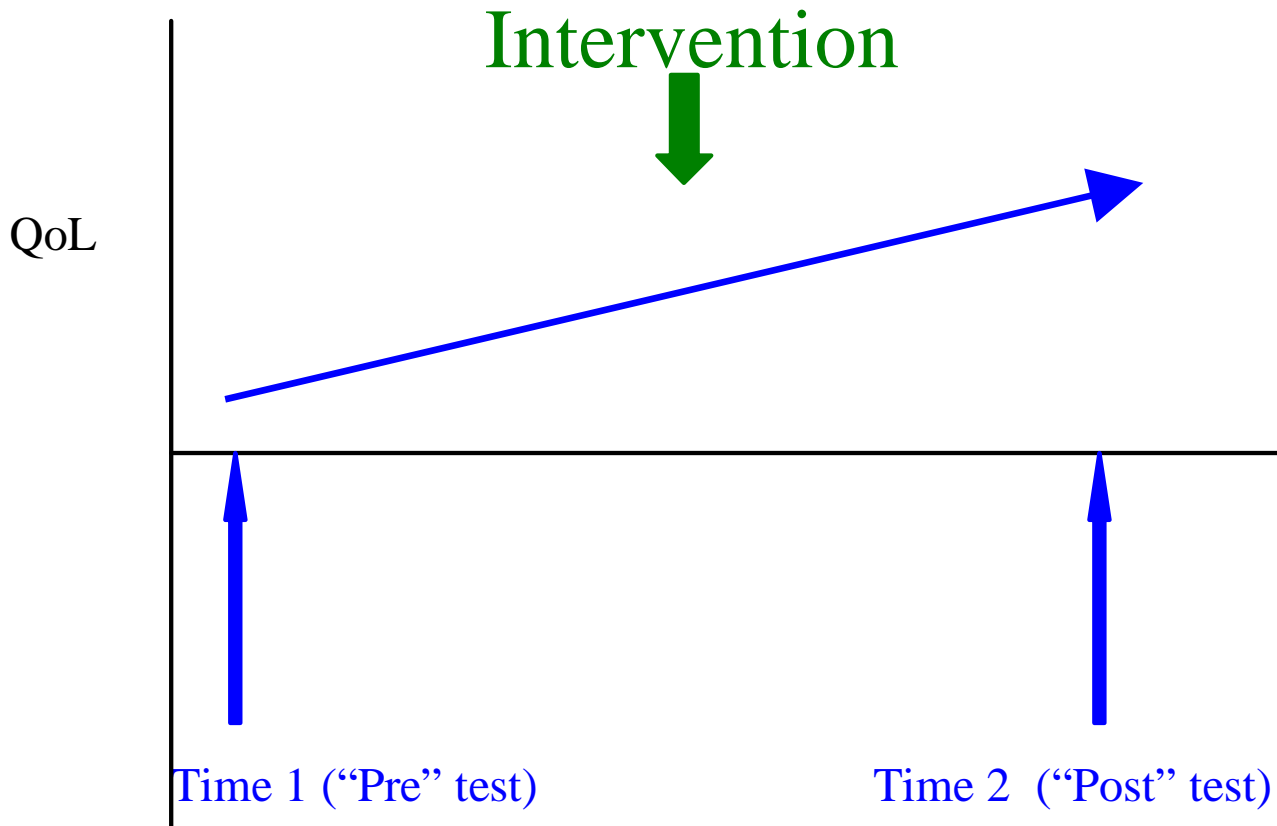


Expectations

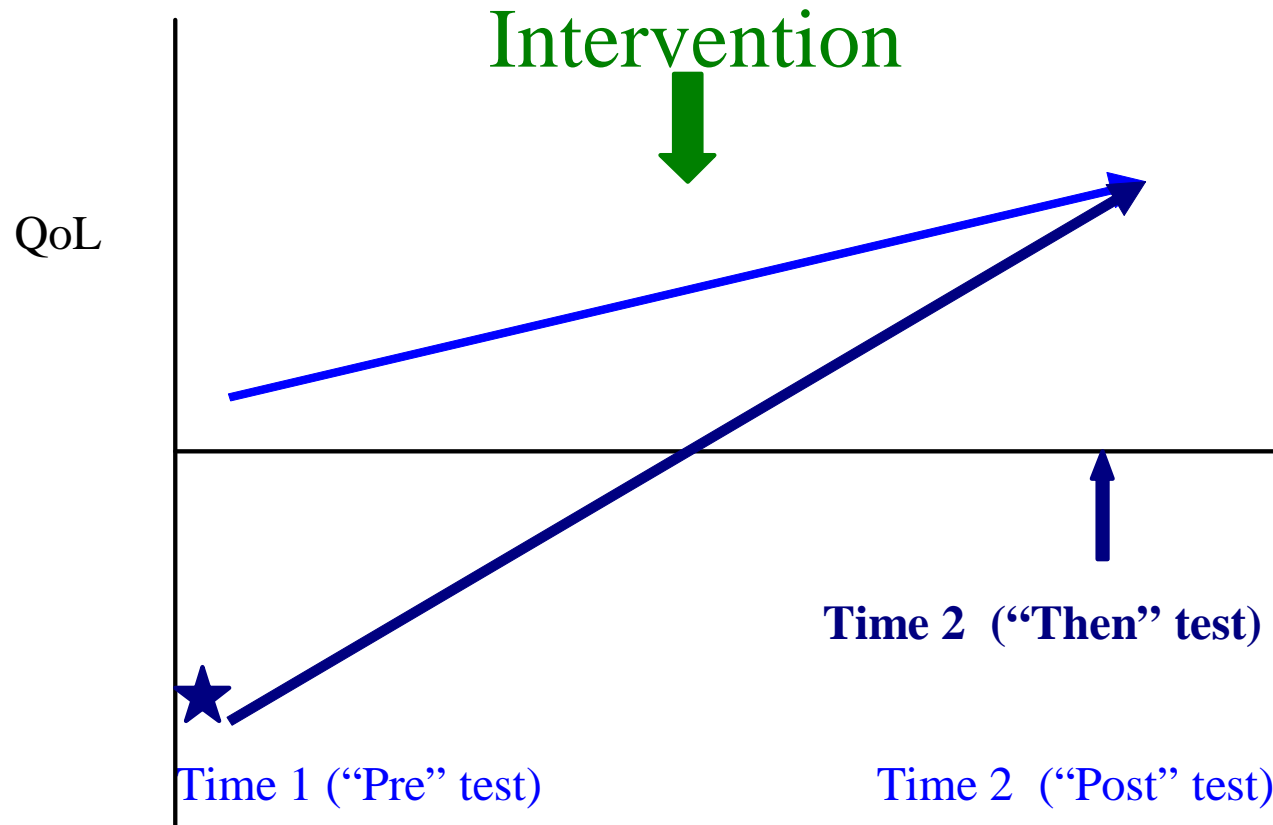
- **Change in *expectations* is a very important aspect of coping and adaptation**
- **Individuals have aims and goals in life, and QoL is a measure of the difference between the hopes and expectations of the individual and the individual's present experience (Calman, 1984)**
- **Perhaps we should be asking about expectations when we measure HRQoL**
- **Perhaps HRQoL instruments should as a routine assess expectations, coping and adjustment**



Quantifying response shift

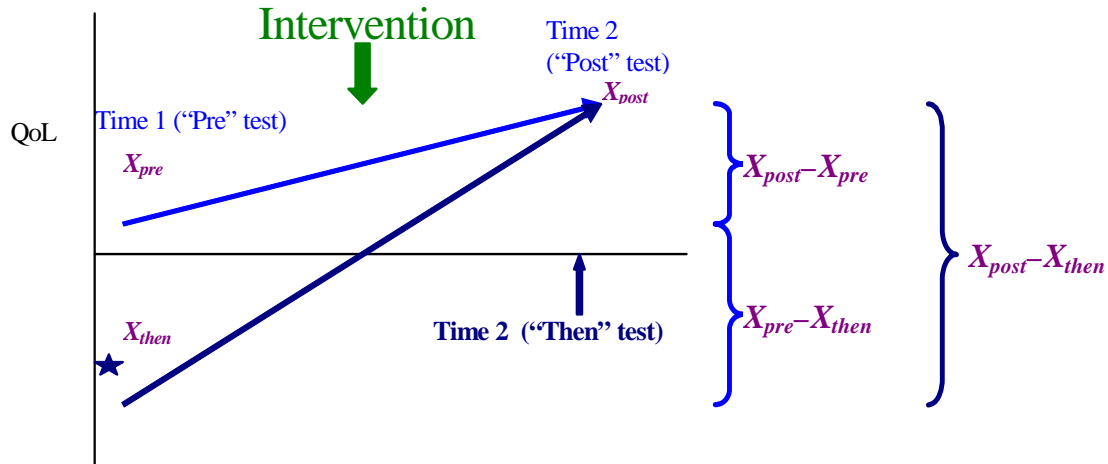


Then-test



- “Can you remember how you felt last time? I would like to ask you to provide a new judgement about the extent to which you were fatigued”

Estimating response shift



Effect of treatment
Observed change $= X_{post} - X_{pre}$

Response Shift $= X_{pre} - X_{then}$

True Change
Observed change + Response shift $= X_{post} - X_{then}$

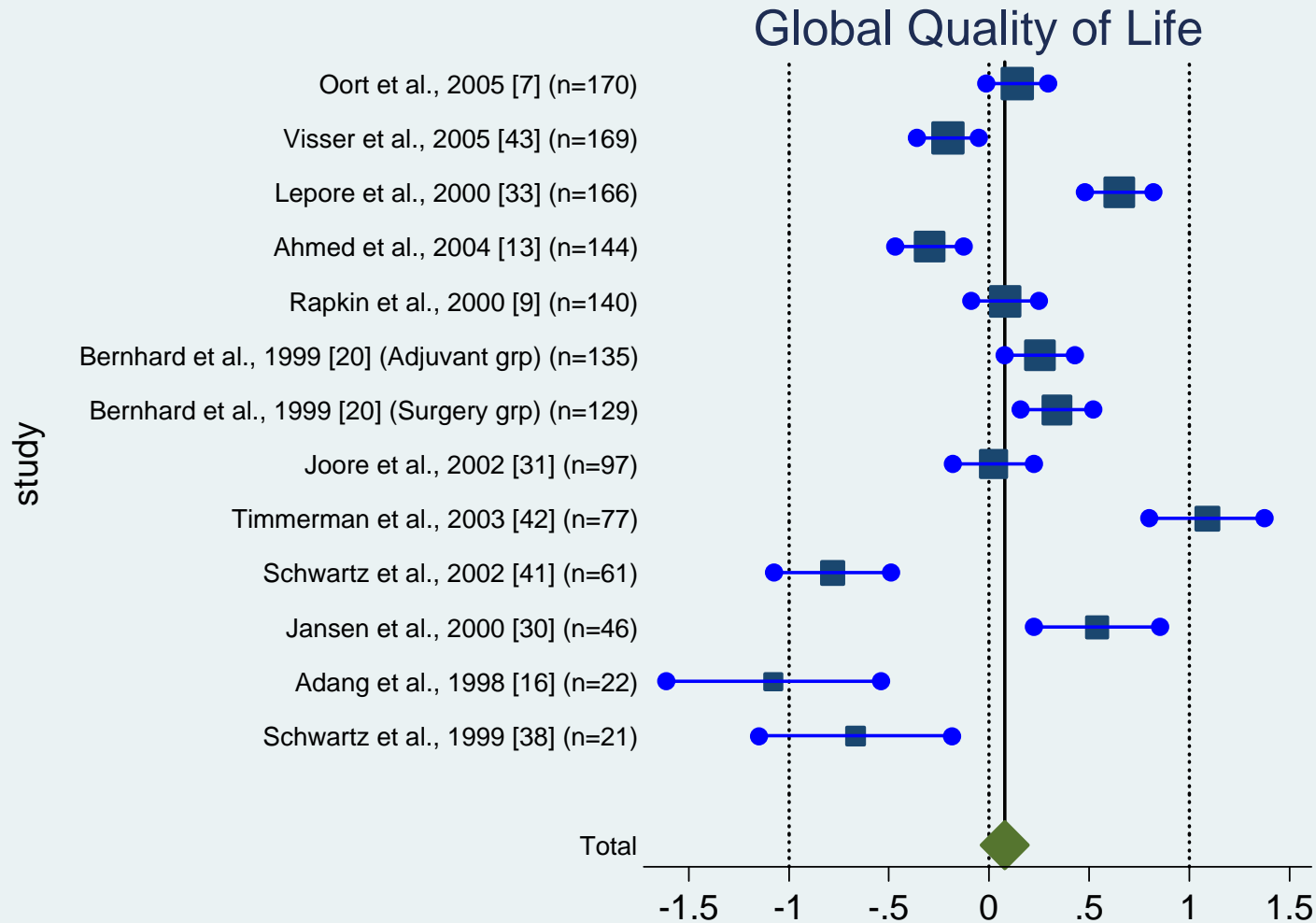
How large is response shift?

- Informal review of published literature:
- 22 empirical papers about response shift in HRQoL.
- *Effect size = mean/S.D.*
- Median *effect size* = 0.25
(0.18 for studies with $n > 100$)
- This (median) corresponds to a small-to-moderate difference in HRQoL scores.
- Some studies reported much larger effect sizes.

Schwartz, Sprangers & Fayers, 2004.



Response Shift – Global Quality of Life



Is then-test useful?

- **Then-test assumes no recall bias.**
- **Then-test assumes that response shift affects the present assessment (e.g. recalibration), which then becomes the “true” value.**
- **There considerable evidence that patients diminish the memory of negative events – forgetting the past.**
- **Memory dims past events – towards neutrality?**



Implicit theories of change

- When asked about change since last visit, patients presumably use heuristics that do not depend on accurate recall of the initial state.
- Judgement is based on an “implicit theory” of change by considering the present state and working backwards – e.g. *“I’ve been steadily improving so my initial state must have been much worse”*.
- From this, patients infer what their initial state must have been.

Norman, 2003



Then-test

- **Hence the then-test may not be valid:**
 - Recall bias
 - Distortion of past events
 - Implicit theories of change

- **Much of response-shift theory was developed in educational fields;**

- **In education, there can be an external referent, an objective assessment.**



Other approaches

- **Qualitative methods**
- **Individualised QoL measures e.g. SEIQoL**
 - Changing priorities.
- **Structural equation modelling (SEM)**
 - Change in factor loadings.
- **Item response theory (IRT) methods**
- **“Ideal state” assessment**
 - Describe the “best-” and “worst-imaginable state” at each time point.



Reference frames

- What do people have in mind when they answer the question:

“How would you rate your overall quality of life?”



Hypotheses

- That different patients would have different reference frames
- That the reported QoL scores *of patients* would vary according to the reference frames
- Sample:
 - N=1325 patients in an RCT
 - Management of Paget's disease
 - SF36, + question about overall QoL



B14. We realise that different people have different things in mind when they answer questions about their 'quality of life'. What things were you thinking about when you assessed your quality of life?

Please write your answers in this box

B15. When you rated your overall quality of life, were you mainly

Comparing yourself against before you became ill?

Comparing yourself against how you felt one year ago?

Comparing yourself against other people with Paget's disease?

Comparing yourself against healthy people that you know (such as friends or family)?

Or thinking of something else?

If you were thinking of something else, please tell us what it was

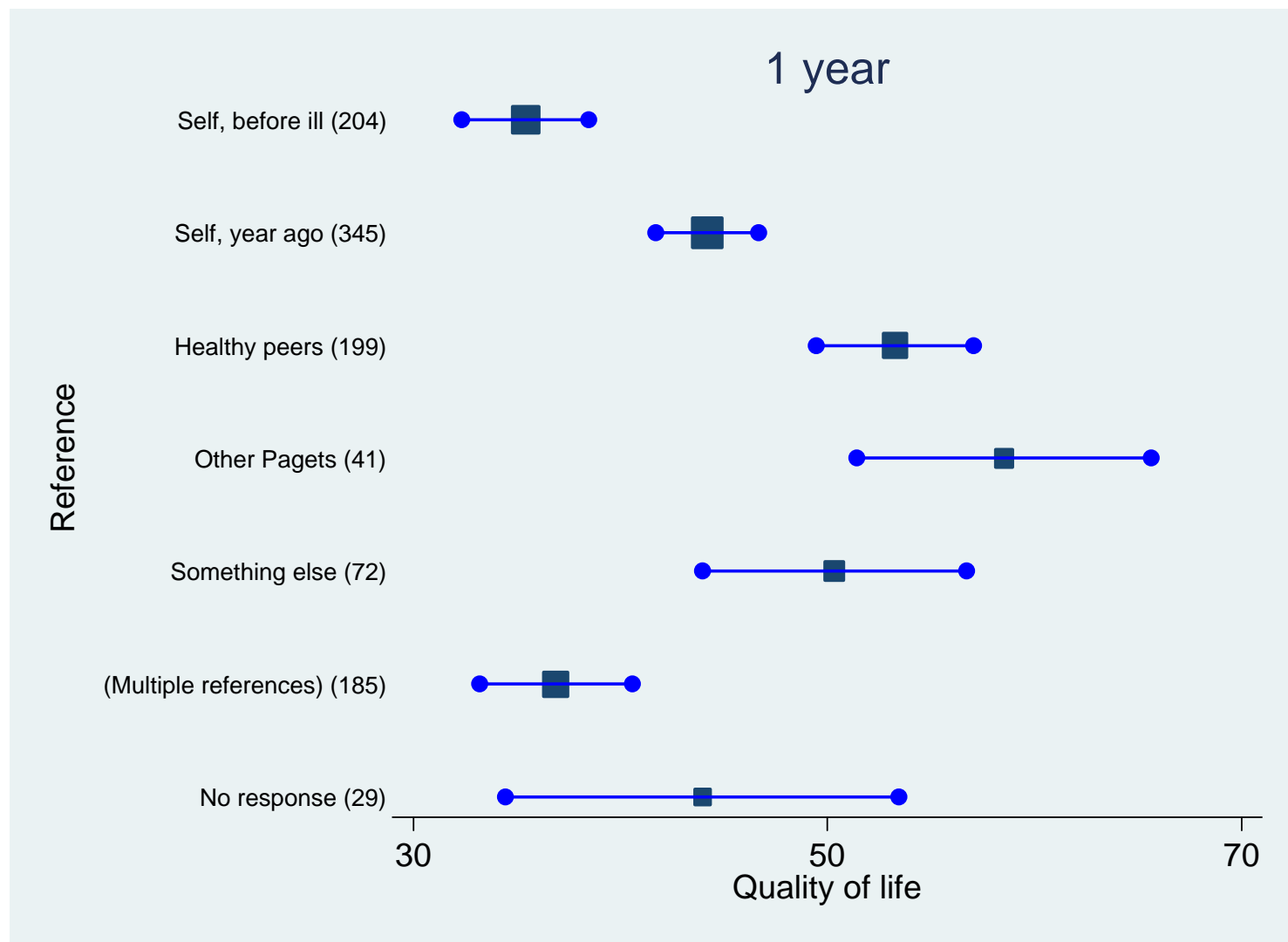
Please write your answers in this box

Results

- **The majority of patients (about 75%) identified a single reference frame.**
- **Approximately,**
 - 22% were thinking about before they were ill
 - 31% were thinking about themselves 1 yr ago
 - 22% had in mind other people
- **Although option 3 was “healthy people that you know”, many respondents qualified this with comments – such as:**
 - “Considering my age, I’m not doing too bad”
 - “Many of my friends are old and ill”



Mean quality of life scores at one year



Results

- The reported QoL and health varied greatly according to the reference frame.
- The mean difference between “self before ill” and “healthy peers” was 18, which is 0.72 standard deviations – a moderate to large effect size.
- A similar magnitude effect was observed at baseline, 1 year and 2 years.



Reference frames – Summary

- **The choice of reference varies over time.**
- **The reference frame has a major impact on reported QoL valuations.**
- **At the very least, a large amount of variation in QoL reports is accounted for by these differences, which are at least as large as those observed in many RCTs.**
- **In some RCTs, e.g. when comparing treatment at home versus treatment in hospital, one might anticipate that the reference frame could obscure QoL differences.**
- **Observational studies, contrasting patients against healthy Norms, may be invalidated.**



Changing reference frames

- **Response shift!**



Does response shift matter?

- **Clinical (pragmatic) perspective:**
 - Clinical trials compare treatment policies, and if one policy of treatment or management results in beneficial (or harmful) response shift, that should be included as part of the treatment effect.
- **Explanatory perspective:**
 - Response shift may distort the estimates of treatment effect.
 - Response shift may obscure potentially important treatment effects, or may overestimate other treatment effects.



The way forward?

- **Maybe it is more realistic to assess the individual mechanisms (coping, etc.), rather than response shift.**
- **The mechanisms represent tangible concepts, for which it may be easier to construct realistic models, e.g., some interventions may improve coping.**



Conclusion

- Response shift certainly occurs.
 - It seems likely that it may distort estimates of changes in HRQoL.
 - The usual method of assessing response shift (*then-test*) is seriously flawed.
-
- Response shift cannot be ignored – but it remains an elusive and challenging concept!

Based on PRISM trial results (reference framing), and book chapter by Schwartz, Sprangers & Fayers, in:

Fayers & Hays (eds.) *Assessing Quality of Life in Clinical Trials: Methods and Practice*. OUP: December, 2004.

