

LOOKING BACK WITH A SMILE

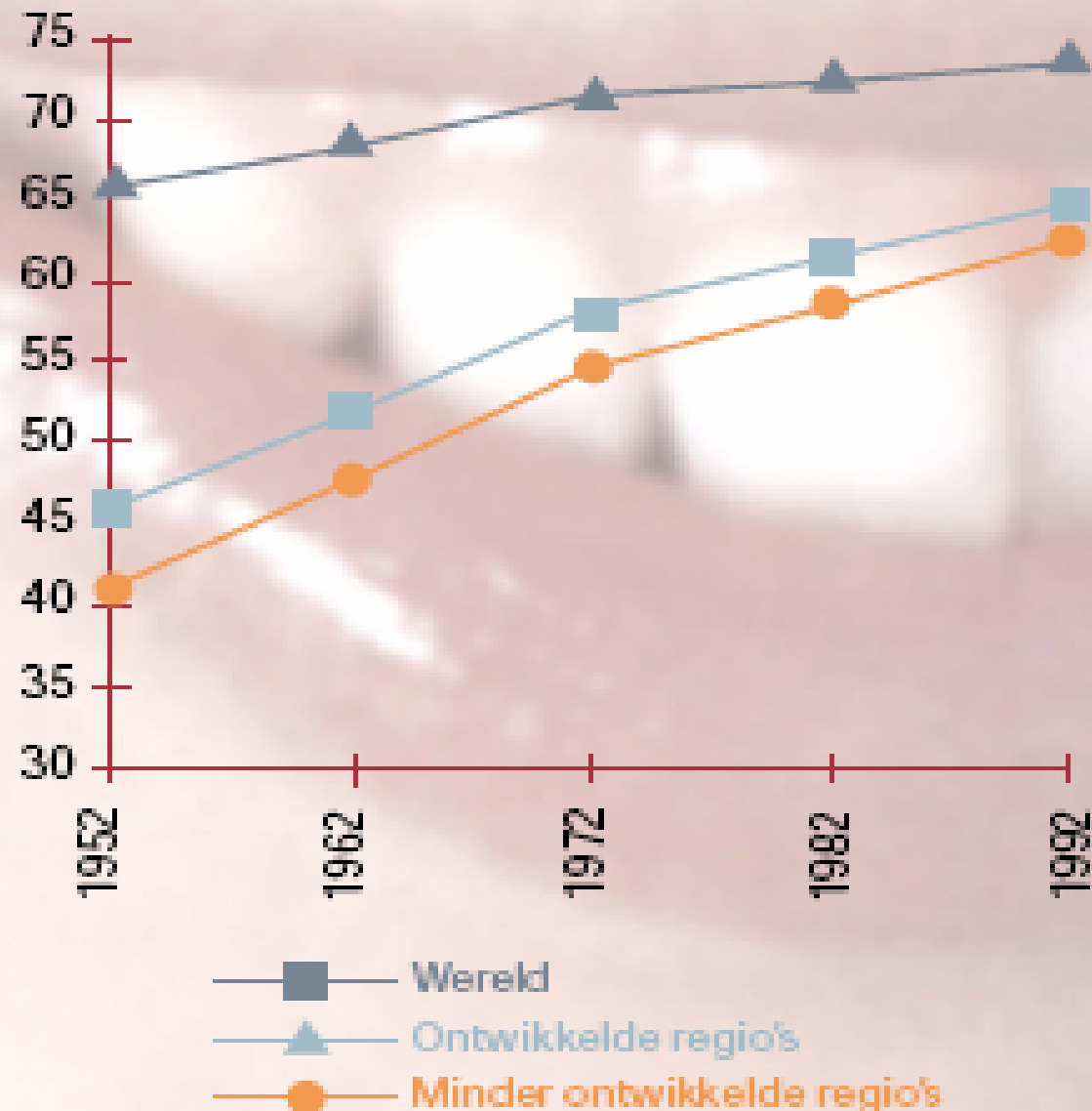
EORTC QOL SG 25th Anniversary
Meeting, Paris, 2006)

Jan L. Bernheim MD PhD

The Beginnings



Figuur 2: Wereldwijde evolutie van de levensverwachting.



Bron: Heylighen F, Bernheim J. Global Progress I: empirical evidence for increasing quality of life. *Journal of Happiness Studies* 2000;1:323-49.

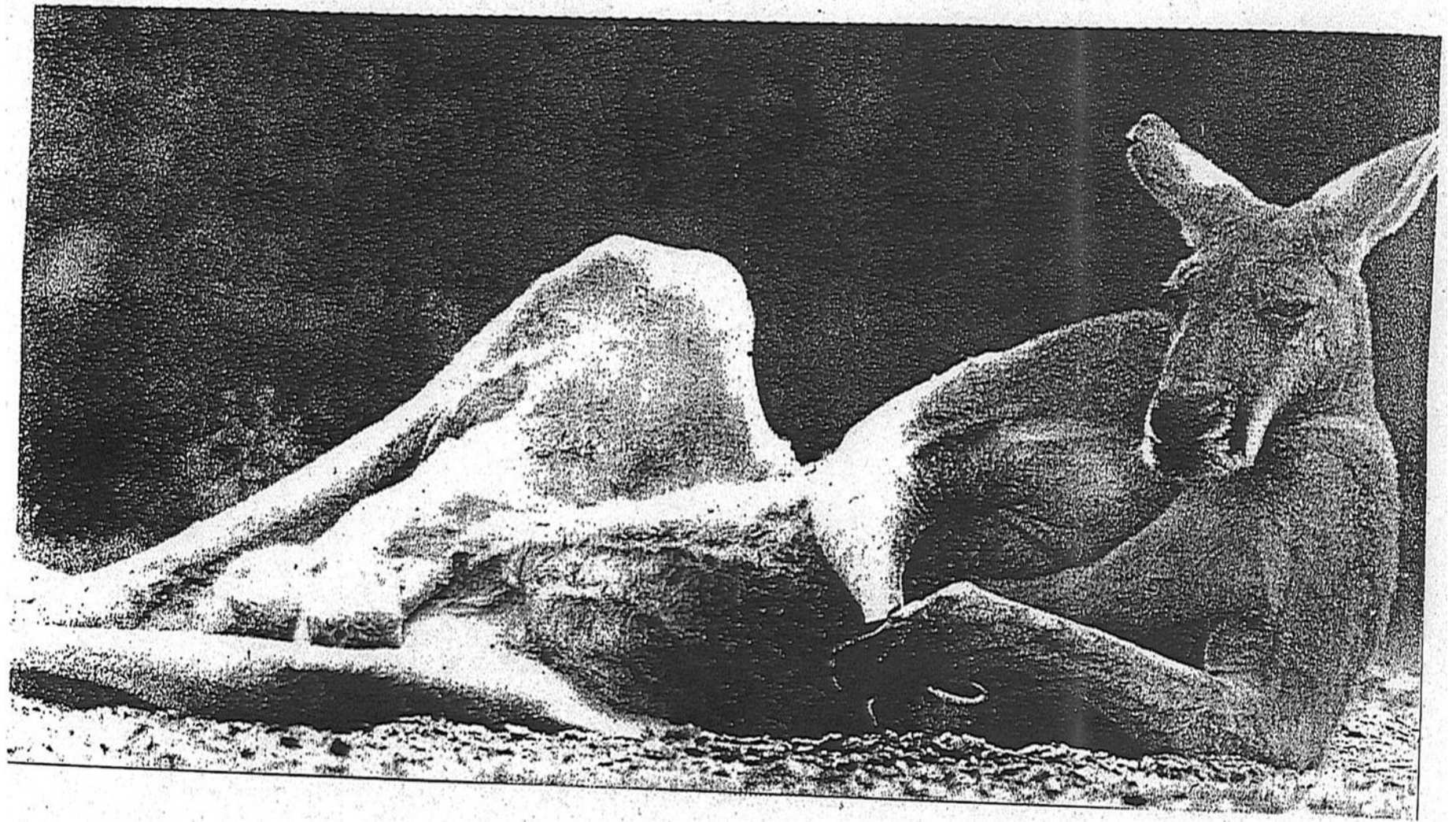
INACCEPTABLE COSTS

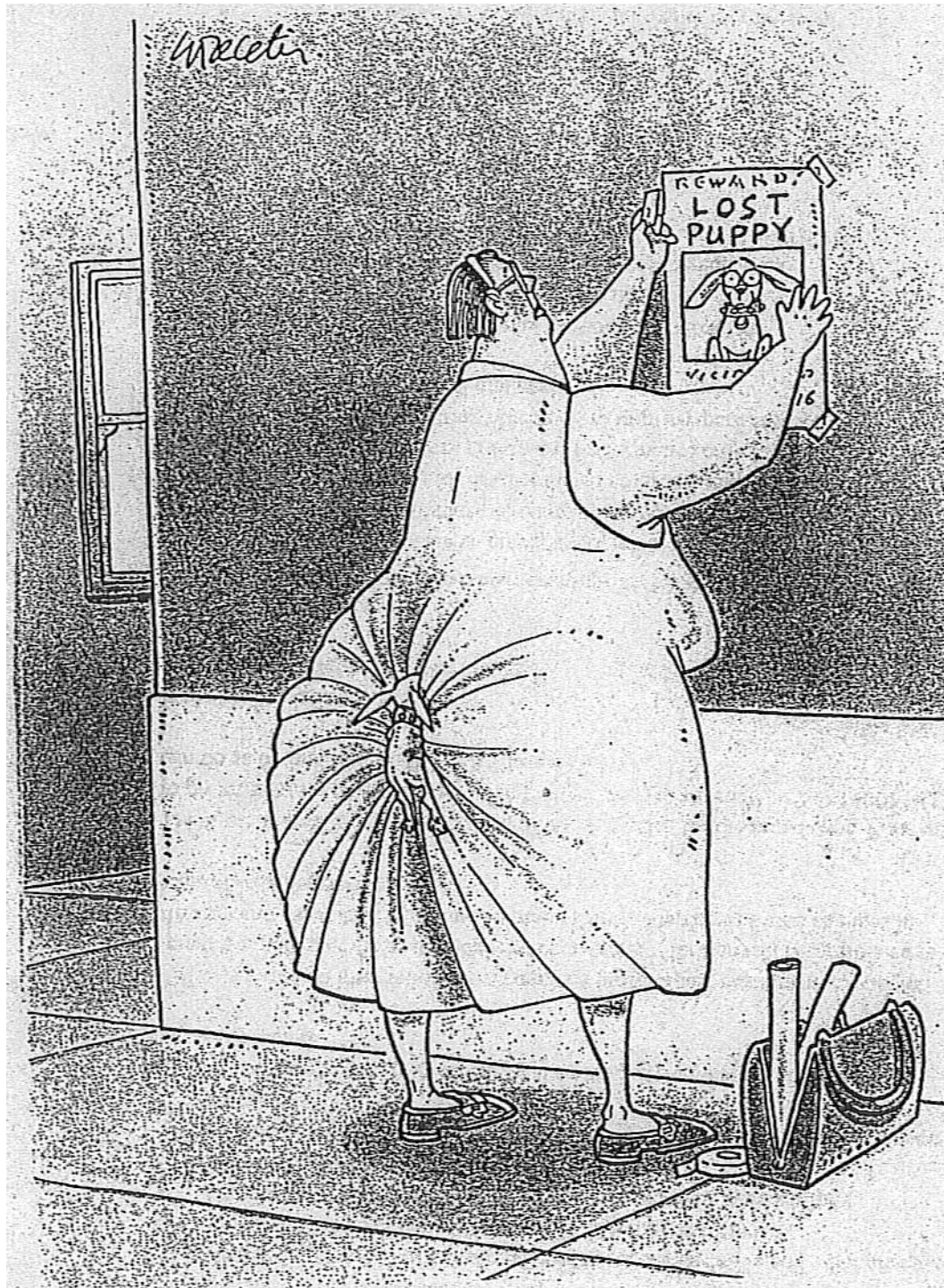
- In cancer treatment, and at the end of life in general, major techniques-driven suffering and costs for poor gains in duration of survival: disproportion and futility ('iatrocities' ?)
- → QOL as an alternative or equally legitimate outcome measure of treatment

***“Measure what is measurable
and make measurable what is not.”***

René Descartes

**For QOL = quantifying quality and making
objective what is essentially subjective**





Objectives of the QLSG

- How to get a serious answer to the serious question: “How have you been?”
- How to scale answers?

The Beginnings

- Multi-disciplinarity
- dissonance
- and dialogue

Requirements of participating tribes

- **CLINICIANS**
 - Quick & Dirty
- **CLINICAL PSYCHOLOGISTS**
 - Patient-centered: let them tell their story
- **PSYCHOMETRICIANS**
 - Validity
 - Reliability, reproducibility
 - Sensitivity, responsiveness
 - Practicability
- **PHILOSOPHICAL ANTHROPOLOGISTS**
 - “Remember Aristotle”

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- **Robert Zittoun 1983:**
- ***Lots of Bility***
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The way I tried to contribute

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TEN HOREN

Wegomlegging

Déviation

Why are multiple item instruments more **descriptive** than **evaluative**, and are **single-item (global) ratings** necessary?

- Multidimensional questionnaires always incomplete
- Individual people have different preferences, which moreover change over time (Response Shifts)
- Dimensions of QoL not independent, but interacting (life = complex, therefore QoL = at emergent level)

Which global question is better suited for what?

Conventional Question (CQ)

I am ...

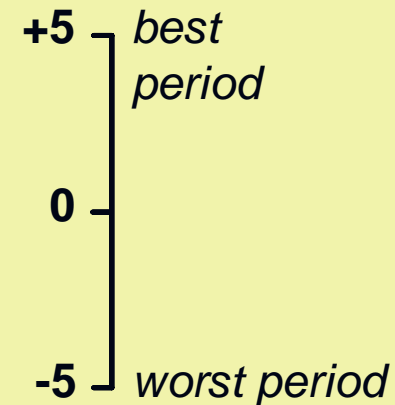
<i>very satisfied</i>	5
<i>satisfied</i>	4
<i>neither/nor</i>	3
<i>unsatisfied</i>	2
<i>very unsatisfied</i>	1

*... with life
as a whole*

OR

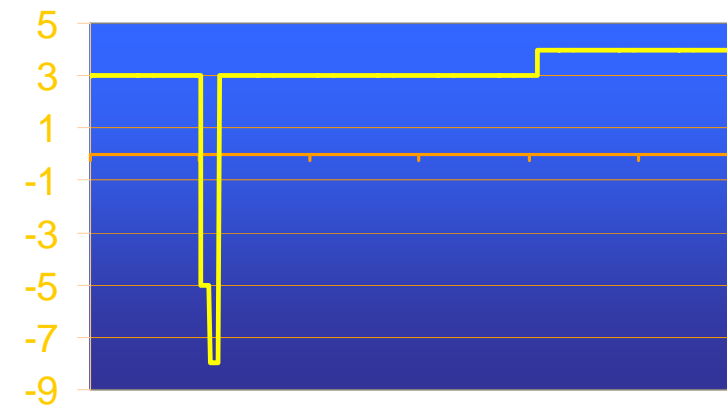
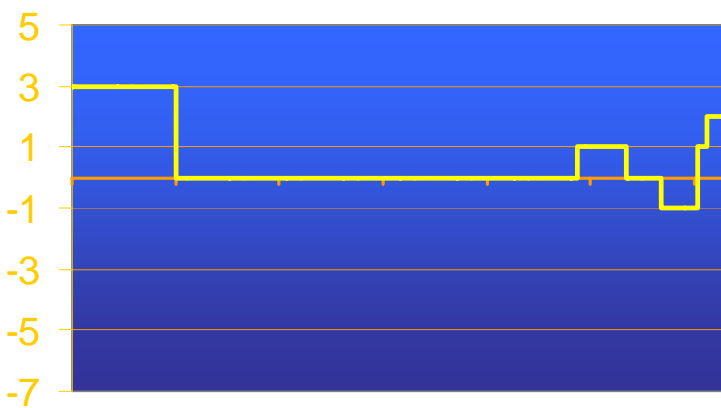
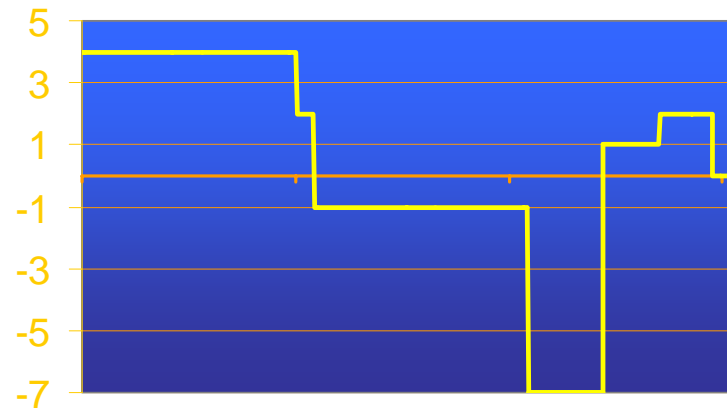
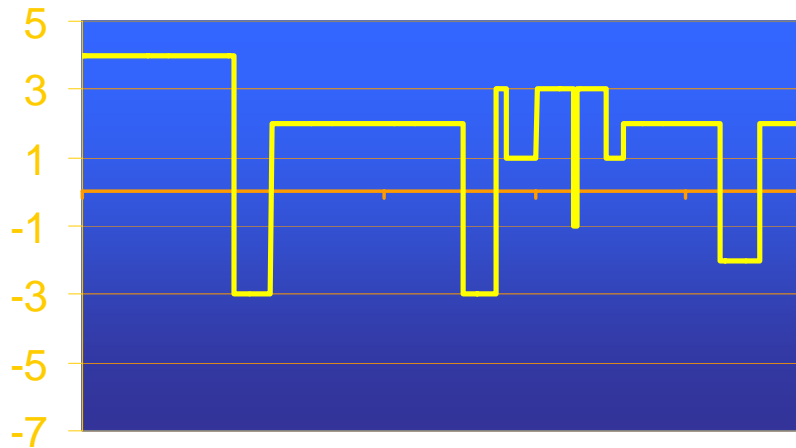
Biographical Question (ACSA)

*On this scale I rate the
current period as ...*



... in my life

Examples of sequential ACSA ratings during illness



Aims

Compare **ACSA** and **CQ** for

- Sensitivity to socio-demographic variables
- Discriminating power
- Responsiveness: sensitivity to objective evolution

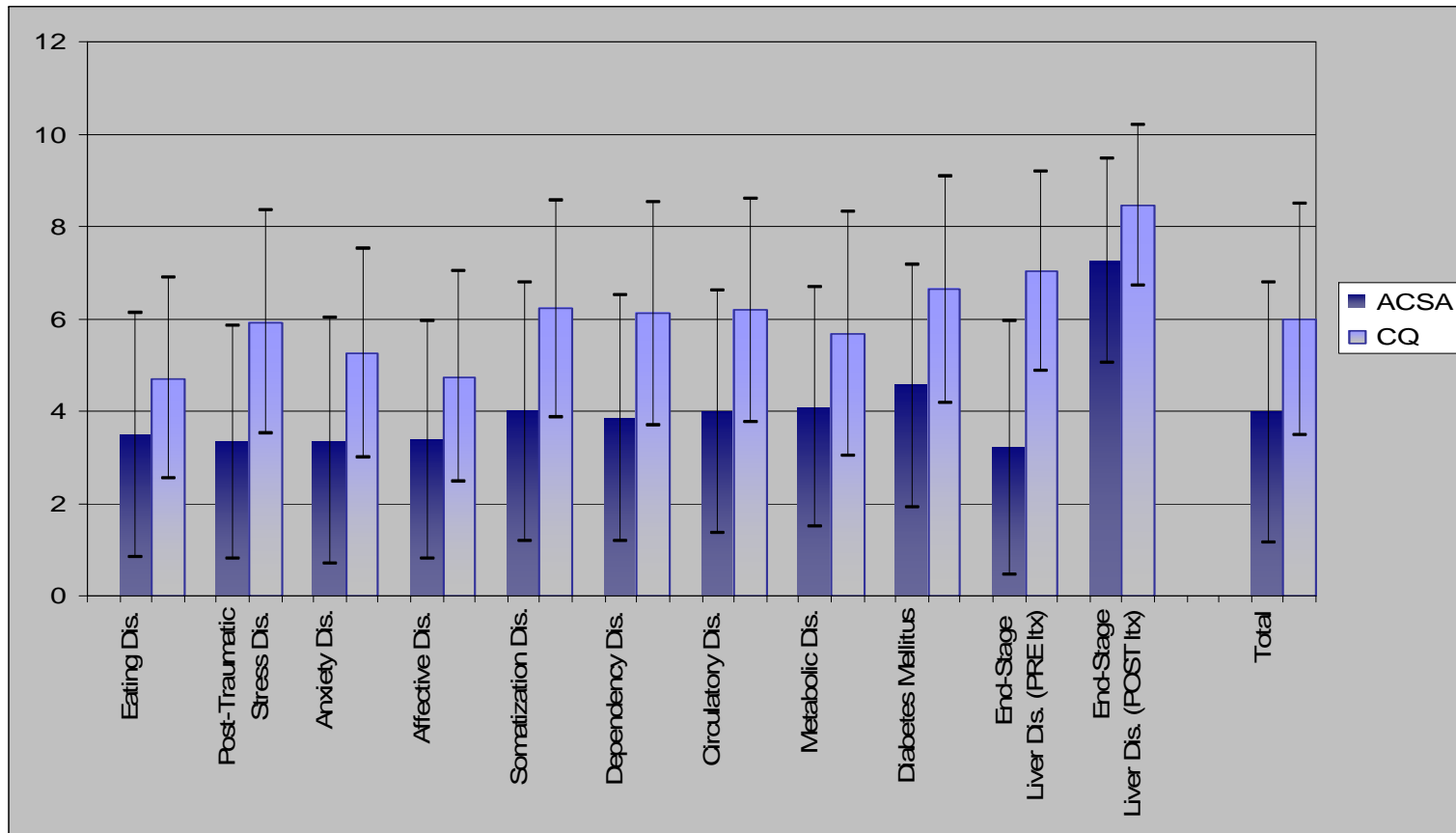
METHODS

n=2545 Berlin general hospital patients replied to both CQ and ACSA, administered as written questionnaires

Eating Dis.	n=305
Post-traumatic Stress Disorder	n=283
Anxiety	n=281
Affective Disorders	n=308
Somatisation Disorders	n=685
Dependency	n=128
Circulatory system.	n=112
Metabolic Disorders	n= 96
End-Stage Liver Dis. (pre transplantation)	n=100
End-Stage Liver Dis. (post transplantation)	n=171
Total	n=2545

Discrimination & Sensitivity to objective change

(CQ and ACSA ratings normalised to 0-10 scale)



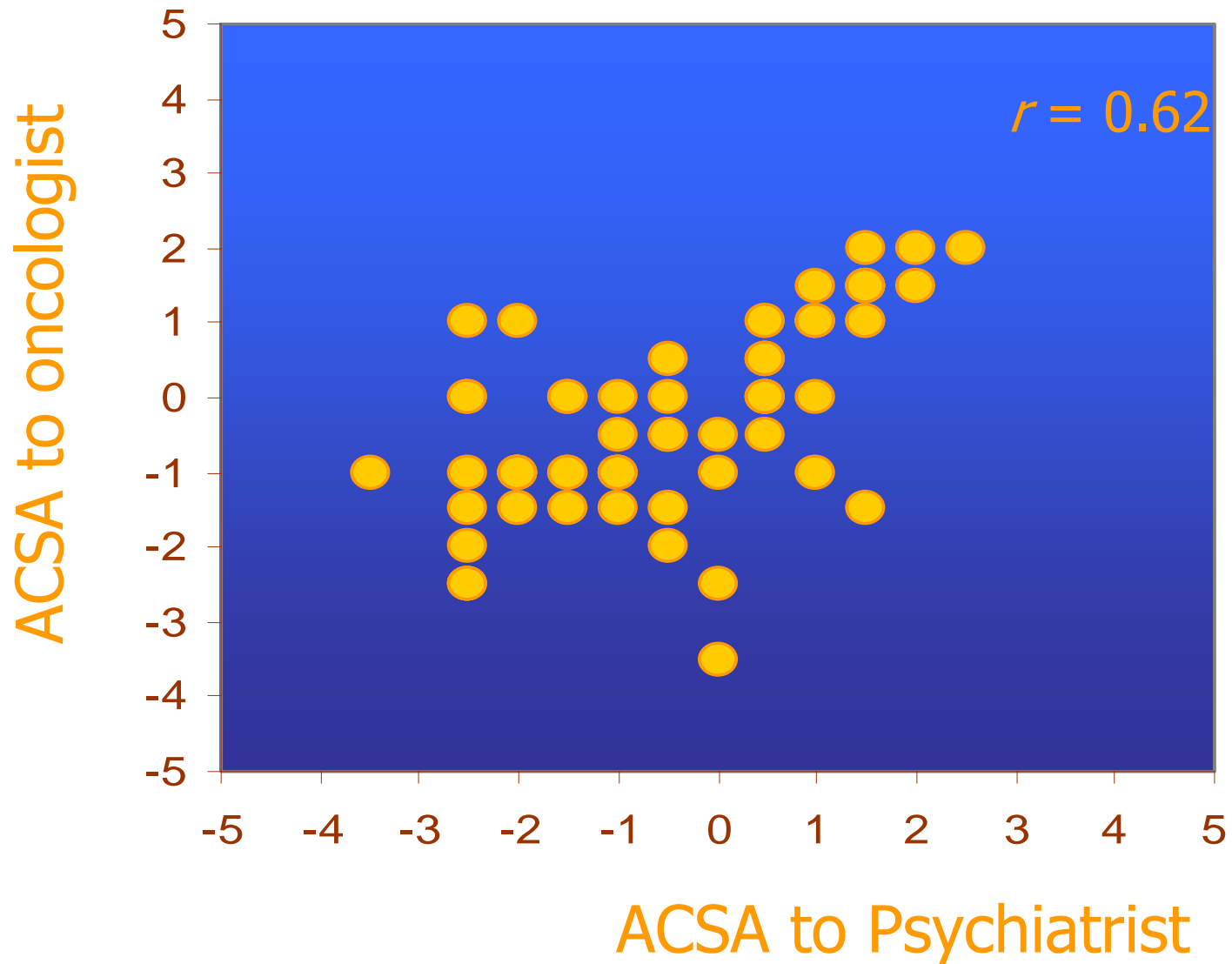
ACSA and Response Shifts

- ACSA less sensitive to response shift: in end-stage liver disease, high ratings with CQ probably reflect response shift (“content to still be alive...”), whereas ACSA ratings are lowest of all disease groups.

Sensitivity to socio-demographic variables

Variables	Beta coefficients	
	Conventional Question	ACSA
Age	.209**	.014
Sex (M=1 / F=0)	-.043*	-.012
Marital status (single or married=1/ widowed or divorced=0)	-.119**	.004
Highest graduation (grammar school or higher=1 / lower=0)	-.015	.007
Employed (Yes=1 / No=0)	-.087**	-.07**
Adjusted R square	.051	.011
** $p \leq 0.01$ level (2-tailed) * $p \leq 0.05$ level (2-tailed)		

ACSA Reproducibility



Conclusions and discussion on ACSA vs CQ

OBSERVATIONS

- ACSA more discriminating
- ACSA more sensitive to objective changes and less to response shift
- ACSA minimally sensitive to socio-demographic variables

POSSIBLE EXPLANATIONS

- Solemn, concrete, individual
- Respondent = his own control
- Use of an **internal** standard with **biographical** references

ACSA TOLERABILITY

(41 Cancer patients expressing themselves to independent psychiatrist)

- Pleased, appreciative: 60%
- Indifferent: 20%
- Annoyed: 20%

Conclusions

- **SENSITIVITY:**
ACSA ratings
 - 1) vary widely cross-sectionally and longitudinally
 - 2) are minimally sensitive to socio-demographic variables
- **RELIABILITY:**
ACSA ratings obtained by different observers are similar for most patients
- **RESPONSE SHIFTS**
 - ACSA ratings less changed:
 -
- **PRACTICABILITY:**
 - Well tolerated, most effective in interview format
 - → **ACSA not so dirty, but not so quick**
 - → **ACSA MAY BE A USEFUL COMPLEMENT TO MULTI-DIMENSIONAL INSTRUMENTS**

May the QL Study Group keep up
the good work

- Taking the long view: the future is no longer what it used to be
- The QLSG is part of an evolutionary paradigm shift from survival and procreation to QOL, from genes to memes