

Quality of Life and Endometriosis

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Health-Related Quality of Life: What is it?

- Multidimensional: encompassing physical, social and psychological aspects
- Patient's point of view is central to the monitoring of disease & associated treatments.

Traditional methods of evaluating outcomes

Mortality

Morbidity, Complications,
Adverse events

(typically based on clinical judgement, radiological data, blood tests etc)

Differences between clinician & patient assessment

- Menstrual symptoms classed as severe by the patient, rated as only moderate by the doctor and vice versa

Coulter et al (1994)

- Estimates of HRQoL only reliable if given by the patient

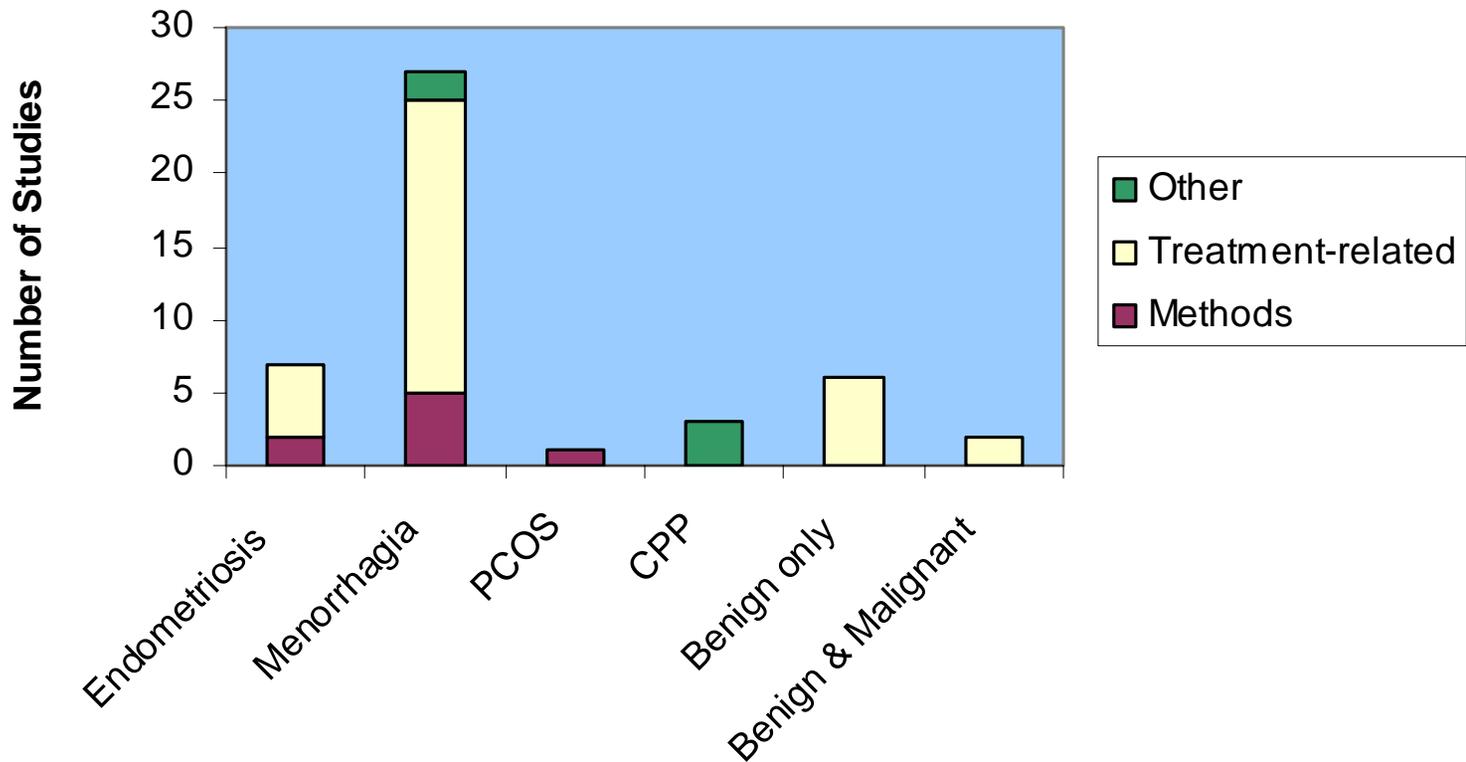
Woodend et al (1997), Present et al (1993)

Qualitative studies

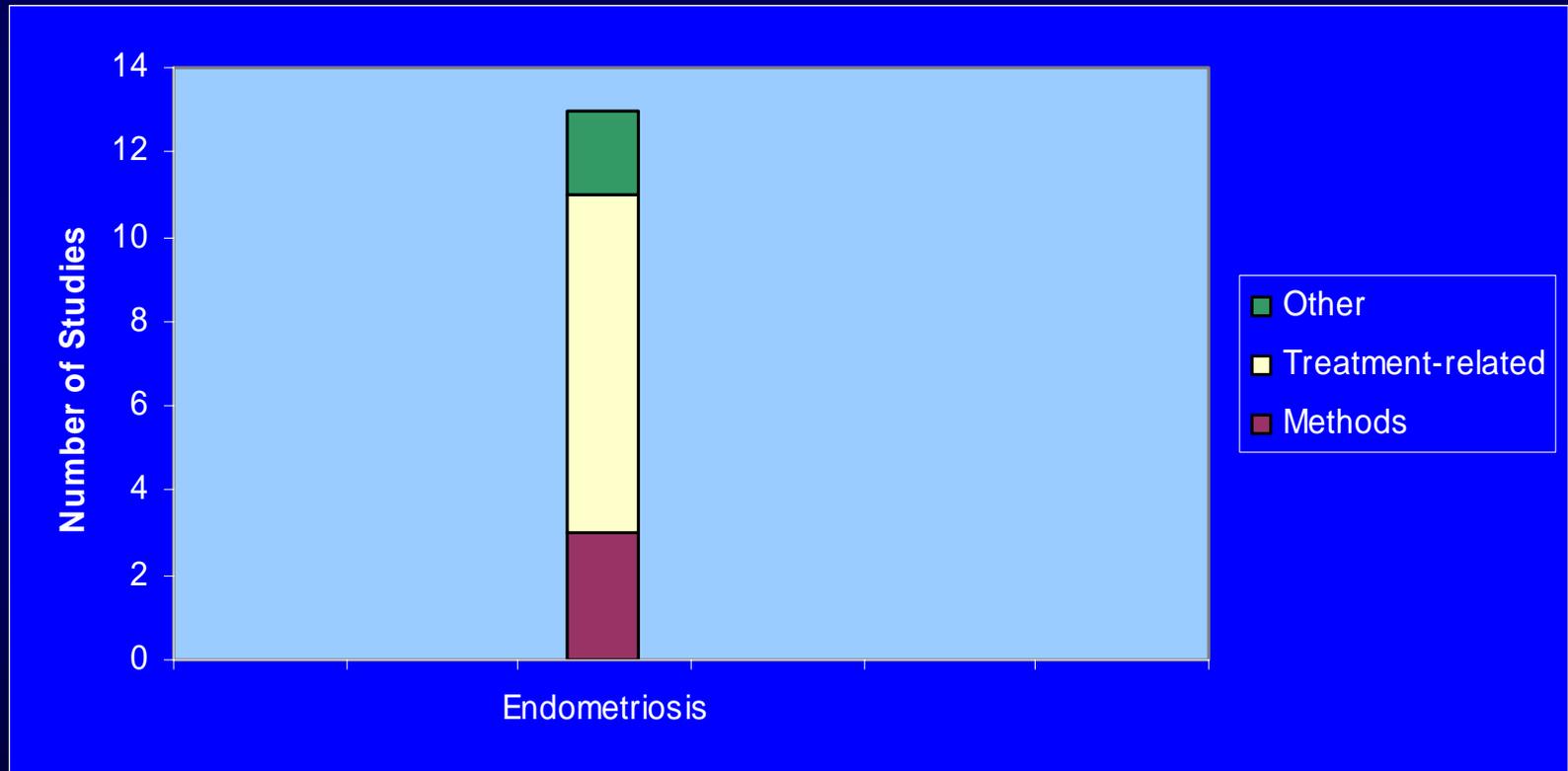
- **Impact multi-dimensional:**
 - Physical appearance, lack of control and powerlessness, feelings of social isolation and concerns that their daughters might develop endometriosis.
- **Impact of the diagnosis:**
 - Frustration in receiving a diagnosis and symptoms frequently trivialized or normalized

(Jones et al, 2004; Denny 2004).

Quality of Life in Endometriosis: Paucity of research up to 2000



Quality of Life in Endometriosis: 2001 – 2006



The Hierarchy of Evidence

- Mainly treatment studies (but focus has been upon surgical Rx).
- Little UK/USA primary research
Brazil, Italy, Australia, France
- UK: mainly review & methods papers
Jones et al (2001; 2002, 2004; 2004; 2006),
2 treatment studies (Ford et al, 2004; Abbott et al 2004)

- Paucity of research in endometriosis using quality of life measures, though slight increase in the last five years
- Incredibly little data on the reliability/validity of measures used in this area

Summary of articles on the HRQoL burden of endometriosis

Most common measures are:

SF-36 and SF-12

EuroQoL EQ-5D

EHP-30 and EHP-5

SF-36

Physical Functioning

Role - Physical

Role - Emotional

Energy/Vitality

Bodily Pain

Social Functioning

Mental Health

General Health Perception

SF-36

**SF-36 contains 36 items
measuring eight domains**

For the most part the measure adopts Likert
type response formats
(for SF-36v2 all questions on Likert typr response formats)

Two summary scores can also be calculated:
Mental Health Component Summary
and the
Physical Health Component Summary

The 36 item Short Form Health Survey SF-36

- The SF-36 was sent as part of a questionnaire pack to women in the Gynaecology Audit Project in Scotland at diagnosis and six months later
- Internal consistency reliability of SF-36 dimensions were found to be high (alpha ranged from 0.79 to 0.91)
- Whilst the SF-36 dimensions were found to be sensitive to the effects of endometriosis the authors claim that the SF-36 was not as responsive to change as condition-specific questions (developed for the project)

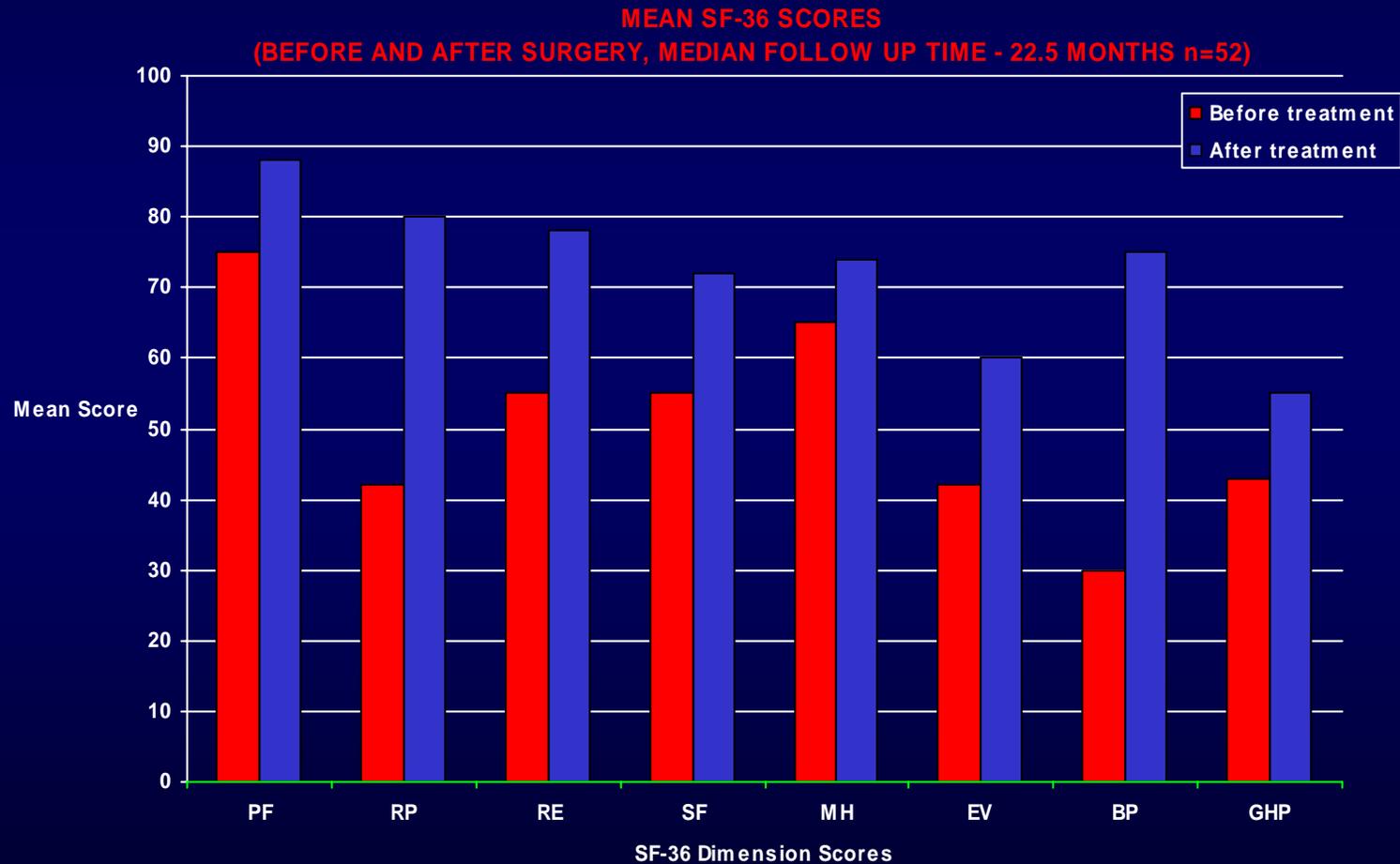
The 36 item Short Form Health Survey SF-36

- Brazilian women with endometriosis-associated pelvic pain (n = 60) had poor SF-36 scores across all domains (i.e. < 50)
- Role Limitations and Physical Functioning scales worst affected
- Interestingly, no correlation found between quality of life and intensity of pain and/or use of medications

(Marques et al, J Reproductive Med 2004; 49: 115-20)

Quality of life after laparoscopic colorectal resection for endometriosis

Quality of life after laparoscopic colorectal resection for endometriosis (Dubernard et al, Hum Reproduction 2006; 21: 1243-47)



Changes on the SF-36

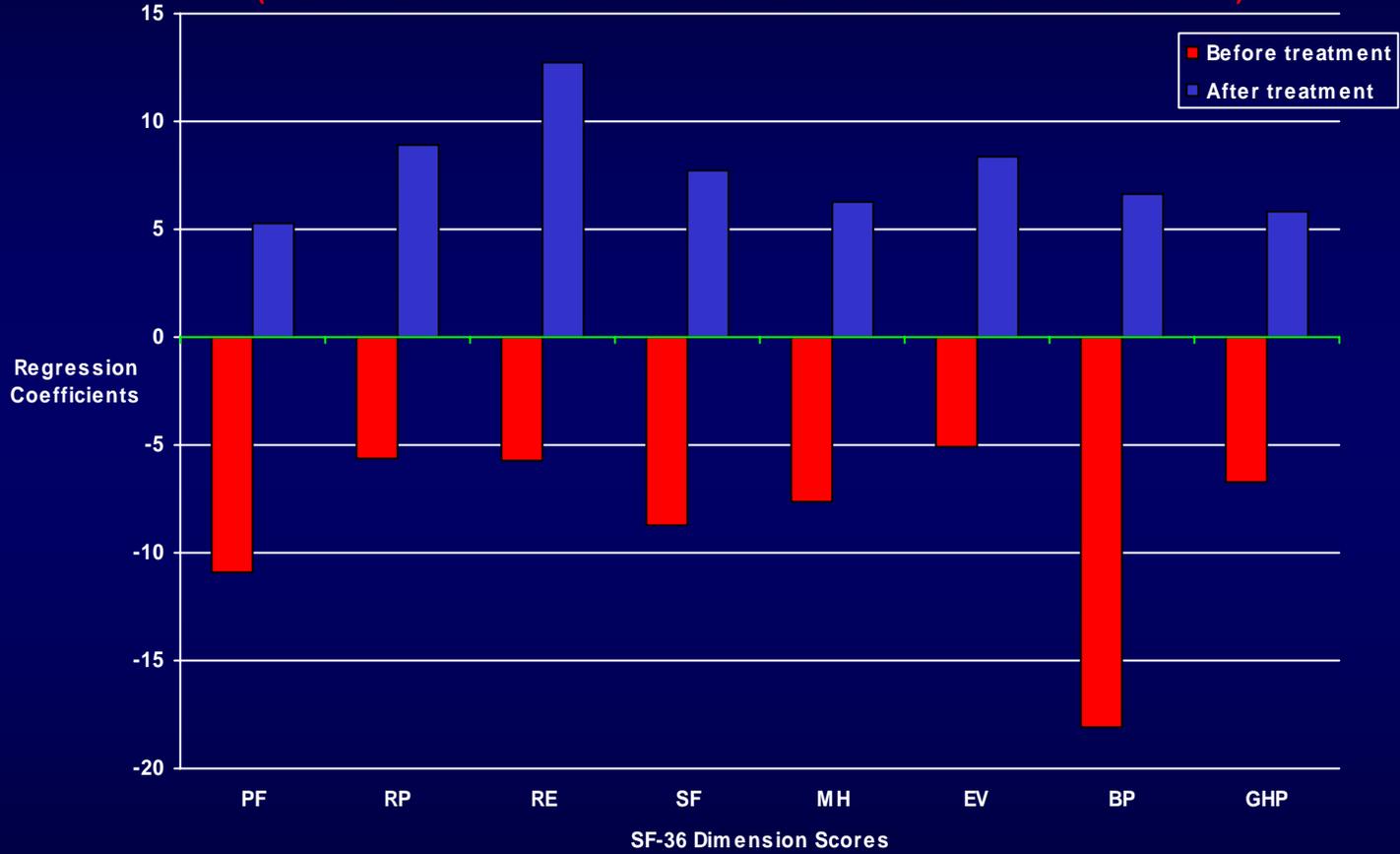
Changes on Role Functioning and Bodily Pain are dramatic (over 40 points). At follow up health state of respondents similar to general population.

Such improvements rarely detected in quality of life studies of treatment regimes.

Can such quality of life data really
make a difference?

Breast Reduction and Quality of Life

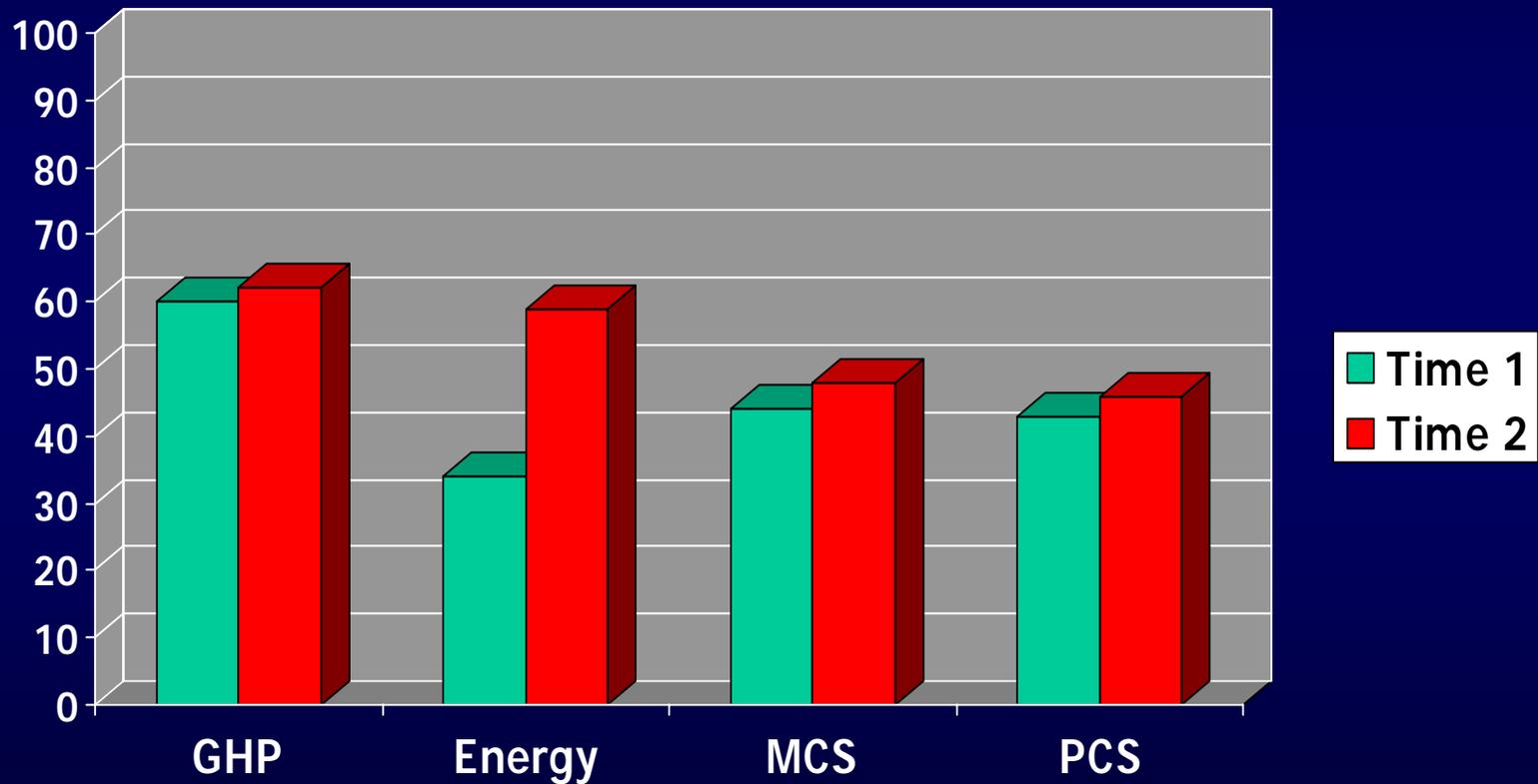
**AGE ADJUSTED MEAN SF-36 SCORES
(BREAST REDUCTION PATIENTS COMPARED TO FEMALE POPULATION NORMS)**



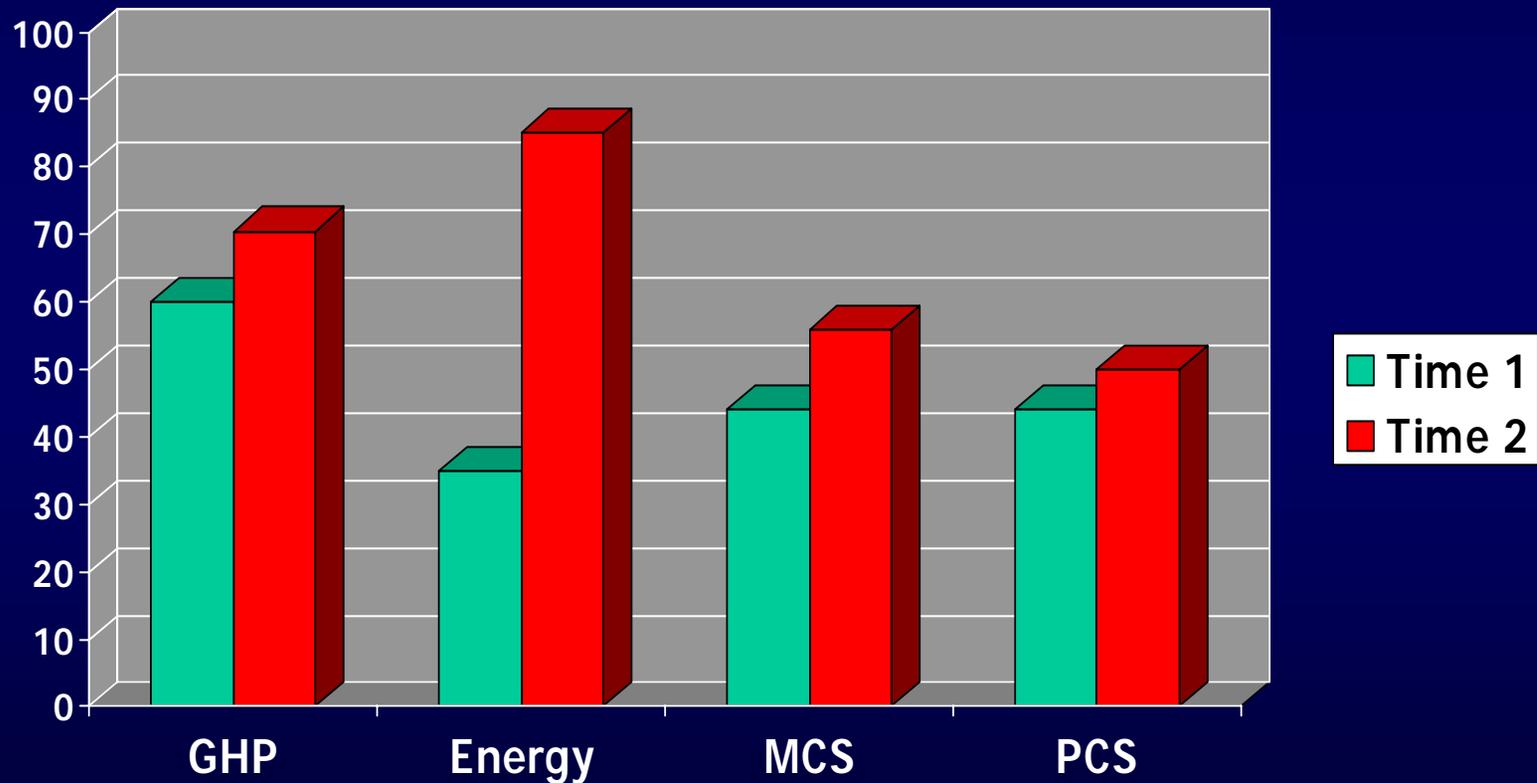
The Oxford NCPAP Trial

Nasal Continuous Positive
Airways Pressure for
Obstructive Sleep Apnoea

One month follow up on SF-36 for placebo group



One month follow up on SF-36 for nCPAP treatment group



SF-12

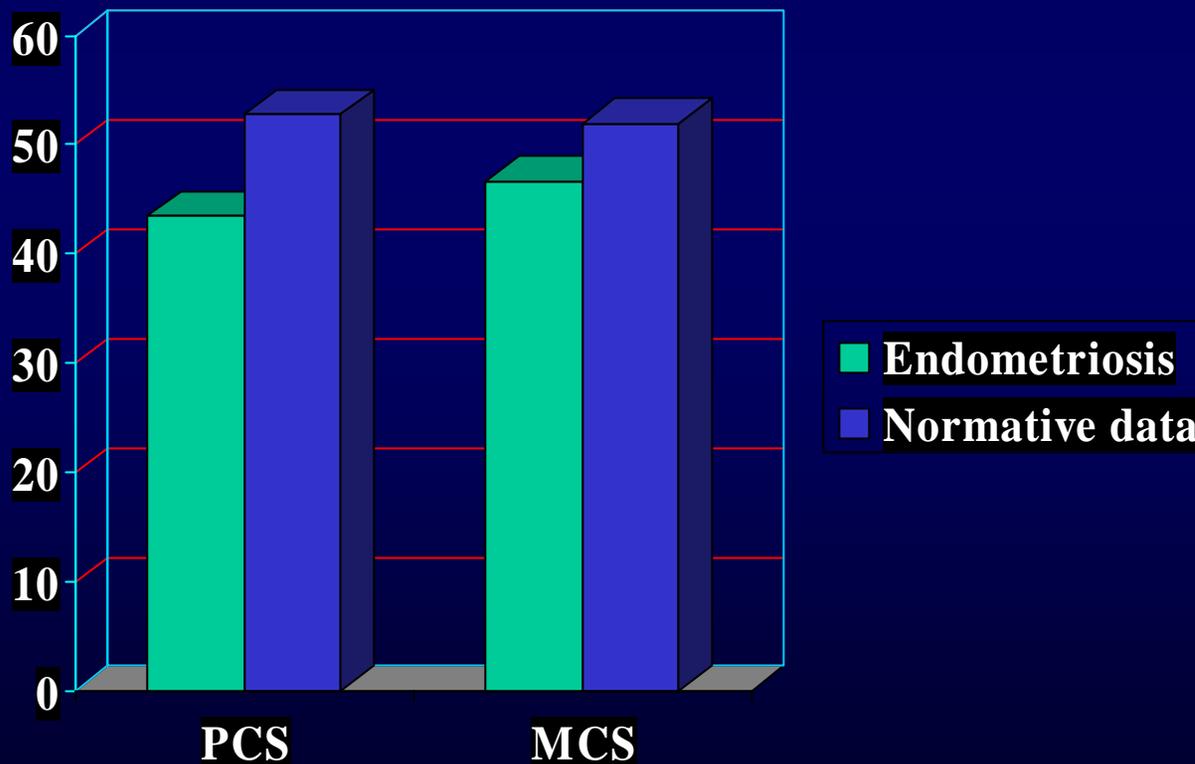
SF-12 contains 12 items intended to replicate the two summary scores of the SF-36

**Mental Health Component Summary
and the
Physical Health Component Summary**

The 12 Item Short Form Health Survey

Comparison of scores on the SF-12 for patients with endometriosis and the general population

(Abbott et al, Hum Reprod 2003;18: 1922-7.)



SF-12 cont.

- SF-12 scores standardised to a mean of 50
- PCS score of 44 is in the bottom 16% of population scores
- MCS of 47 is in the bottom third of population scores.

EuroQoL EQ-5D

Mobility

Self-care

Usual activities

Pain/Discomfort

Anxiety /Depression

EuroQoI EQ-5D

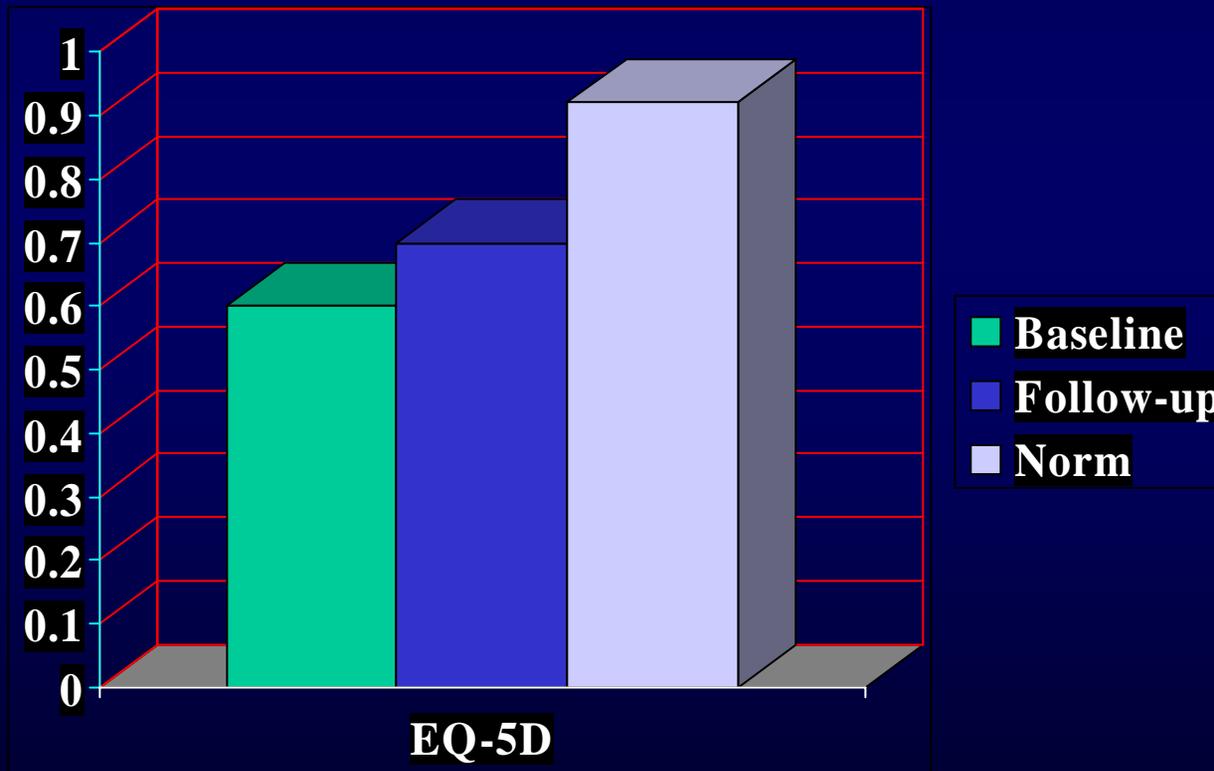
**Produces a single index of
health state**

**Utility based measure based
upon societal valuations**

**Time trade off methodology
used to calculate tariffs**

EQ-5D results in endometriosis

254 women follow up for five years after laparoscopic excision for endometriosis.



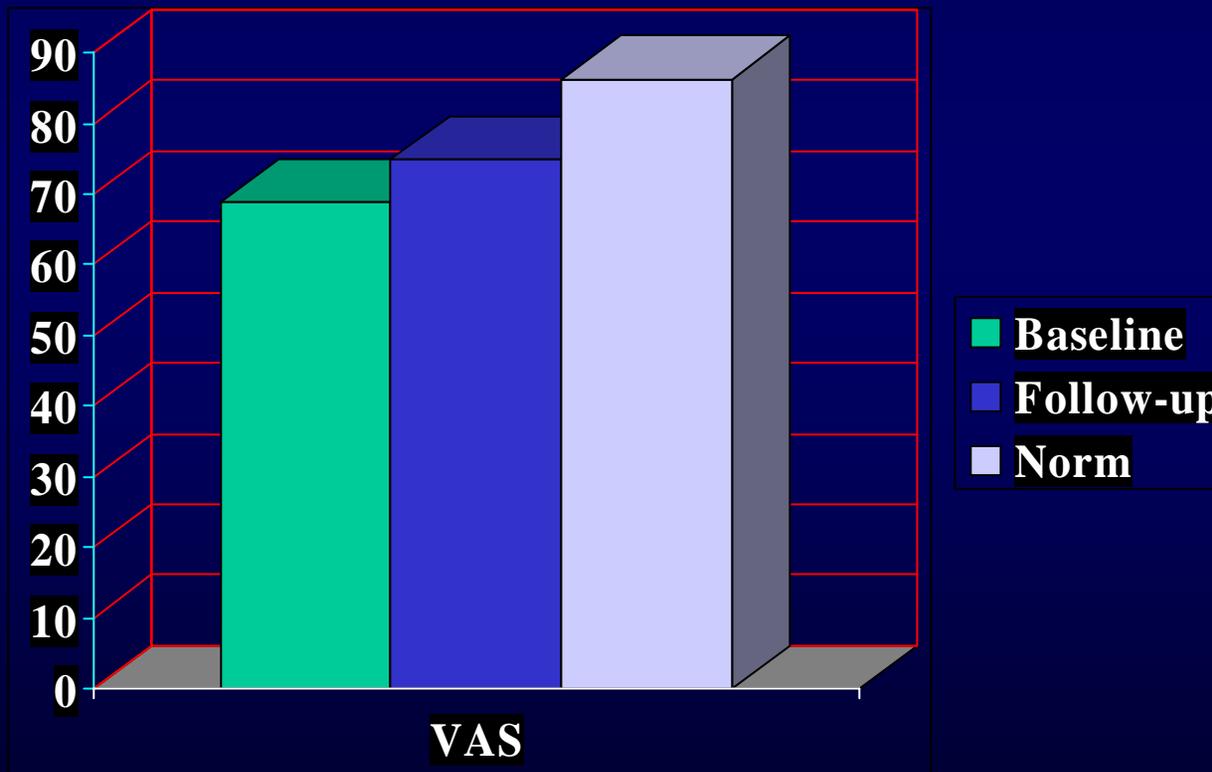
EQ-5D interpretation

Score of 0.92 reflects almost perfect health.

A score of 0.60 indicates moderate levels of Pain and Discomfort, Anxiety and Depression, and problems performing Usual Activities and Self Care. A score of 0.70 at follow up indicates a small improvement in health.

EQ-5D VAS results in endometriosis

254 women follow up for five years after laparoscopic excision for endometriosis.



However generic measures not always sensitive to treatment

“A sensitive qualitative instrument for measurement of quality of life in patients with endometriosis was difficult to find. Most instruments have been developed for an older population with chronic diseases. The quality of life profiles used in the U.S. study are generally not sensitive enough to differentiate between danazol and nafarelin”.

(Burry, AJOG, 1992; 166: 735-9.)

Endometriosis Health Profile (EHP)

- Core Domains:
Pain (11 items), emotional well-being (6 items), control & powerlessness (6 items), social support (4 items) and self-image (3 items).
- Modular Domains:
Work (5 items), relationship with children (2 items), sexual intercourse (5 items), infertility (4 items), medical profession (4 items), treatment (3 items)

(Jones et al, 2001, 2006)

The EHP-30 Development and Validation

- Item generation -
 - qualitative interviews with 25 women (~ 1 hour)
 - audiotaped + transcribed to identify main themes
 - Initial 87 item questionnaire

Scale Generation and Item Reduction

Mean age: 32.5 years [SD] 7.2

min = 17 years, max = 58 years (n=325)

Mean period since diagnosis: 32 months, SD [44]

min = 1 month: max = 360 months: (n = 323)

- Factor analytic techniques used to help determine dimensions of the EHP-30 and item content.
- Cronbach's Alpha statistic was calculated to check the internal consistency reliability i.e. the extent to which items in a scale tap an underlying dimension (Alpha found to be high on all core and module scales, ranging from 0.79 – 0.93).

Responsiveness of the EHP-30

EHP Dimensions

Pain	1.8
Control and Powerlessness	2.3
Emotional well-being	1.1
Social support	0.6
Self image	0.9

Selected SF-36 Dimensions

Physical Functioning	0.7
Energy/Vitality	1.3
Pain	1.0
Social Functioning	1.1

(women undergoing conservative surgery,
Jones et al Quality of Life Research 2004; 705-13.)

EHP-30 and EHP-5

- A single overall index score can be calculated from the EHP-30
- EHP-5 short form available
- EHP-30/EHP-5 Manual available

Conclusions

- Limited research undertaken on quality of life and endometriosis.
- Very few papers evaluating the measurement properties of instruments when used in endometriosis.
- EHP-30/EHP-5 only well validated disease specific quality of life scales.