

Patient Centred Outcomes Research Section 20 years Celebration Event

Patient-centred care: the role of quality of life and
psychosocial research (up to 1996)

Peter Selby



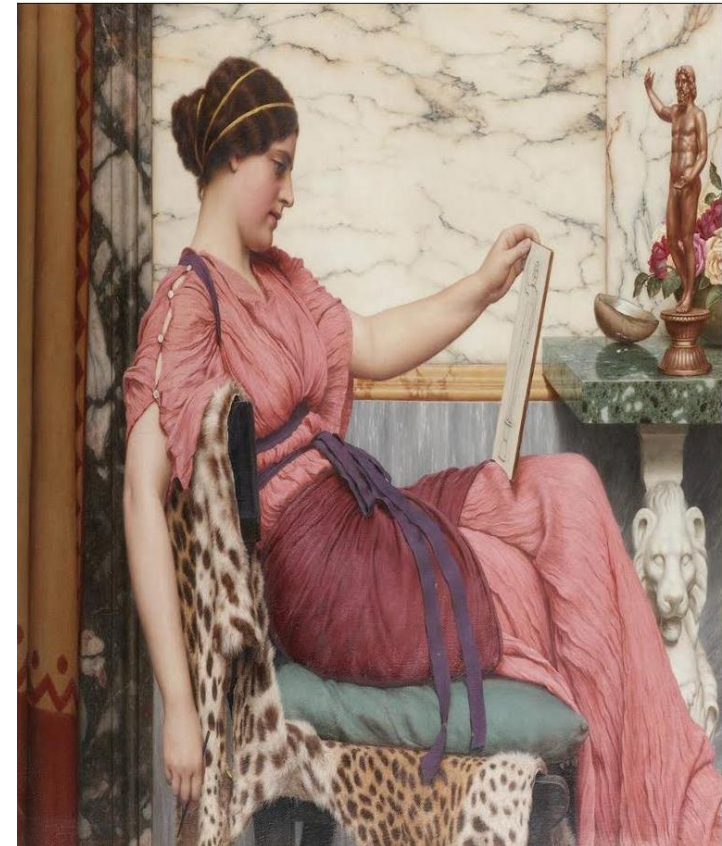
Overview of Quality of Life and Psychosocial Research

What lessons can we learn from the early years that are still relevant today?

Why bother?

*“Those who cannot remember
the past are condemned to repeat it”*

George Santayana (1905)
The Life of Reason:
Reason in Common Sense p284



Psychosocial oncology and patient centred care

What were the issues when we began?

- How to provide cancer care which took account of the patients' perspectives
- How to understand what matters – what is benefit?
- How to measure what matters to patients in addition to survival
- How to integrate impacts on patients which could be opposites eg symptom relief vs toxicity
- What tools existed, or could be made, to drive forward a patient centred approach

Psychosocial oncology and patient centred care

Lesson 1

Measurement science helps to define concepts, shape strategies and alter behaviours

Lesson 2

Measurement of health related quality of life in cancer provided a key to unlock the door to patient centred care

Broad beginnings in psychometrics, measuring “IQ” and psychiatry measuring “mood”

Bringing measurement into oncology practice

EVALUATION OF QUALITY OF LIFE IN PATIENTS RECEIVING TREATMENT FOR ADVANCED BREAST CANCER

T. J. PRIESTMAN

M. BAUM

Combined Breast Cancer Clinic, Cardiff

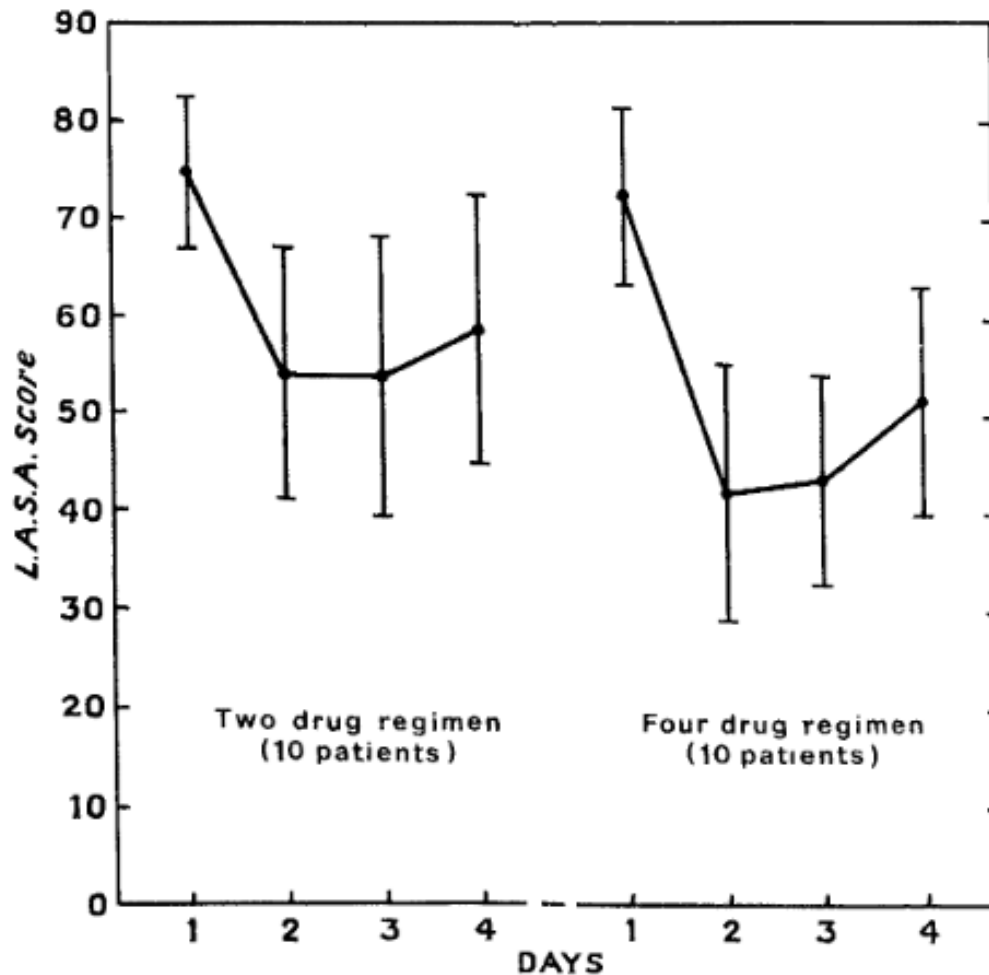
THE LANCET, APRIL 24, 1976

LINEAR ANALOGUE

SELF-ASSESSMENT TECHNIQUE

“For a given variable (eg nausea) a 10 cm line is drawn, and the ends of the line are labelled with words descriptive of extremes of that symptom. The patient is asked to mark the line at a point most appropriate to her feelings at that moment; the distance, in centimetres, along the line to the mark gives a score out of ten.”

Linear Analogue Self-Assessment Technique measures by breast cancer patients



The development of a method for assessing the quality of life of cancer patients

**Departments of Medicine and Bioresearch,
Princess Margaret Hospital and Ontario Cancer
Institute, Toronto, Ontario, Canada and the
Royal Marsden Hospital, Sutton, UK**

*Selby, Chapman, Etazadi-Amoli, Dalley & Boyd
British Journal of Cancer (1984), 50, 13-22*

The development of a method for assessing the quality of life of cancer patients

PLEASE SCORE HOW YOU FEEL YOUR LIFE HAS BEEN AFFECTED BY
THE STATE OF YOUR HEALTH (ANY DISEASE OR TREATMENT)
DURING TODAY (24h).

You may like to look back over the previous scales and consider the scores you have made and how much you feel they have affected your life.

My life is
extremely unpleasant
because of the
state of my health

My life is normal
for me with no
changes because of
the state of my
health

**30 items derived from the Sickness Impact Profile
and a Breast cancer module**

*Selby, Chapman, Etazadi-Amoli, Dalley & Boyd
British Journal of Cancer (1984), 50, 13-22*

The development of a method for assessing the quality of life of cancer patients

Reliable

Test-retest reliability of items

<i>Disease related item</i>			
<i>Item</i>	<i>r</i>	<i>Item</i>	<i>r</i>
Dysuria	0.85	Sore mouth	0.68
Attractiveness	0.84	Breathing	0.66
Pain	0.83	Fatigue	0.66
Information	0.79		
Constipation	0.79	Diarrhoea	0.37
Hair loss	0.78	Nausea	0.32
Appearance	0.78	Vomiting	0.25
		Uniscale	0.72

Selby, Chapman, Etazadi-Amoli, Dalley & Boyd
British Journal of Cancer (1984), 50, 13-22

The development of a method for assessing the quality of life of cancer patients

Valid

Correlations between items: factor analysis

Factor 4

Nausea	(0.86)
Vomiting	(0.85)
Eating	(0.38)

Selby, Chapman, Etazadi-Amoli, Dalley & Boyd
British Journal of Cancer (1984), 50, 13-22

The development of a method for assessing the quality of life of cancer patients

Valid

Correlations between items: factor analysis

Factor 5

Attractiveness	(0.64)
Family relations	(0.63)
Hair loss	(0.35)

Selby, Chapman, Etazadi-Amoli, Dalley & Boyd
British Journal of Cancer (1984), 50, 13-22

The development of a method for assessing the quality of life of cancer patients

Correlation of item scores with Sickness Impact Profile categories

Instrumental Comparisons

<i>Direct comparisons</i>	
<i>Item</i>	<i>r</i>
Work	0.97
Housework	0.71
Overall score	0.70
Physical activity	0.65

Selby, Chapman, Etazadi-Amoli, Dalley & Boyd
British Journal of Cancer (1984), 50, 13-22

The development of a method for assessing the quality of life of cancer patients

Doctor/patient correlations

Disease related item

<i>Item</i>	<i>r</i>
Diarrhoea	0.98
Constipation	0.89
Hair loss	0.80
Breathing	0.80
Fatigue	0.74
Pain	0.72
Attractiveness	0.66
Vomiting	0.64

Selby, Chapman, Etazadi-Amoli, Dalley & Boyd
British Journal of Cancer (1984), 50, 13-22

The development of a method for assessing the quality of life of cancer patients

Doctor/patient comparison

<i>Item</i>	<i>r</i>
Family relations	0.70
Housework	0.69
Concentration	0.66
Anxiety	0.60
Depression	0.58
Increased sleep	0.37
Speech	0.29
Anger	0.11

Lesson 3

Patient self report

Selby, Chapman, Etazadi-Amoli, Dalley & Boyd
British Journal of Cancer (1984), 50, 13-22

Assessing quality of life in cancer patients **UK (1989)**

The widespread feeling that quality of life should be measured in clinical trials has led to requests for guidance from the Cancer Therapy Committee of the Medical Research Council and other bodies as to the best available methods at present.

Assessing quality of life in cancer patients UK (1989) – clinical trials

- 1) The current “best-bet” for tapping key dimensions of quality of life is the Rotterdam symptom checklist.
- 2) When additional items are needed to assess illness or treatment related variables which are not covered by the RSCCL these can be added in categorical form.
- 3) The hospital anxiety and depression scale appears particularly useful in assessing levels of anxiety and depression in cancer patients. *(Dr Philip Snaith)*
- 4) Linear analogue systems are useful.

Assessing quality of life in cancer patients
USA (1989) – clinical trials

**Quality of Life End Points in Cancer Clinical
Trials: Review and Recommendations**

Carol McMillen Moinpour, Polly Feigl, Barbara Metch, Katherine
A. Hayden, Frank L. Meyskens, Jr., John Crowley*

USA (1989)

The key policies recommended by us and adopted by the Cancer Control Research Committee of the Southwest Oncology Group are as follows:

- a) Begin assessment of quality of life in specific types of phase III protocols.**
- b) Always measure physical functioning, emotional functioning, symptoms (general and protocol specific), and global quality of life separately.**
- c) Include measures of social functioning and additional protocol-specific measures if resources permit.**
- d) Use patient-based questionnaires with psychometric properties that have been documented in published studies.**

Overview at 1990

- **Measurement science for HRQL was established and was driving research – especially in clinical trials**
- **Patient centred healthcare services were subjects for discussion**
- **Major successful measurement initiatives were being made in Europe and the USA**

The European Organization for Research and Treatment of Cancer QLQ-C30: A Quality-of-Life Instrument for Use in International Clinical Trials in Oncology

*Neil K. Aaronson, Sam Ahmedzai, Bengt Bergman, Monika Bullinger, Ann Cull, Nicole J. Duez, Antonio Filiberti, Henning Flechtner, Stewart B. Fleishman, Johanna C. J. M. de Haes, Stein Kaasa, Marianne Klee, David Osoba, Darius Razavi, Peter B. Rofo, Simon Schraub, Kommer Sneeuw, Marianne Sullivan, Fumikazu Takeda for the European Organization for Research and Treatment of Cancer Study Group on Quality of Life**

J Natl Cancer Inst, 1993 Mar 3;85(5):365-76

EORTC QLQ-C30

- **In 1986, the EORTC initiated a program to develop an integrated, modular approach for evaluating the quality of life of patients in clinical trials.**
- **The QLQ-C30 incorporates nine multi-item scales: five functional scales (physical, role, cognitive, emotional, and social); three symptom scales (fatigue, pain, and nausea and vomiting); and a global health and quality-of-life scale.**
- **Several single-item symptom measures are also included.**
- **It's practical, reliable and valid.**

The Functional Assessment of Cancer Therapy Scale: Development and Validation of the General Measure

By David F. Cella, David S. Tulsky, George Gray, Bernie Sarafian, Elizabeth Linn, Amy Bonomi, Margaret Silberman, Suzanne B. Yellen, Patsy Winicour, Judy Brannon, Karen Eckberg, Stephen Lloyd, Sandy Purl, Carol Blendowski, Michelle Goodman, Madeline Barnicle, Irene Stewart, Marnie McHale, Philip Bonomi, Edward Kaplan, Samuel Taylor IV, Charles R. Thomas, Jr, and Jules Harris

“We developed and validated a brief, yet sensitive, 33-item general cancer quality-of-life (QL) measure for evaluating patients receiving cancer treatment, called the Functional Assessment of Cancer Therapy (FACT) scale.”

Psychosocial oncology and patient centred care

Lesson 4

Measuring things is a “big hit” with people who like measuring things!

Calman Hine Report (April 1995)

Seven principles to govern the provision of cancer care

- Access to uniform high-quality care in the community or hospital
- Early identification of cancer and availability of national screening programmes
- Patients to be given clear information at all stages
- Services to be patient centred
- Centrality of primary care and effective communications
- Psychosocial aspects of care are important
- Cancer registration and monitoring of treatment and outcome are essential



Welsh Office
Y Swyddfa Gynreig

A POLICY FRAMEWORK FOR COMMISSIONING
CANCER SERVICES

*A REPORT BY THE EXPERT ADVISORY
GROUP ON CANCER TO THE CHIEF
MEDICAL OFFICERS OF ENGLAND AND
WALES*

What do we mean by “Patient Centred”?

England 1995

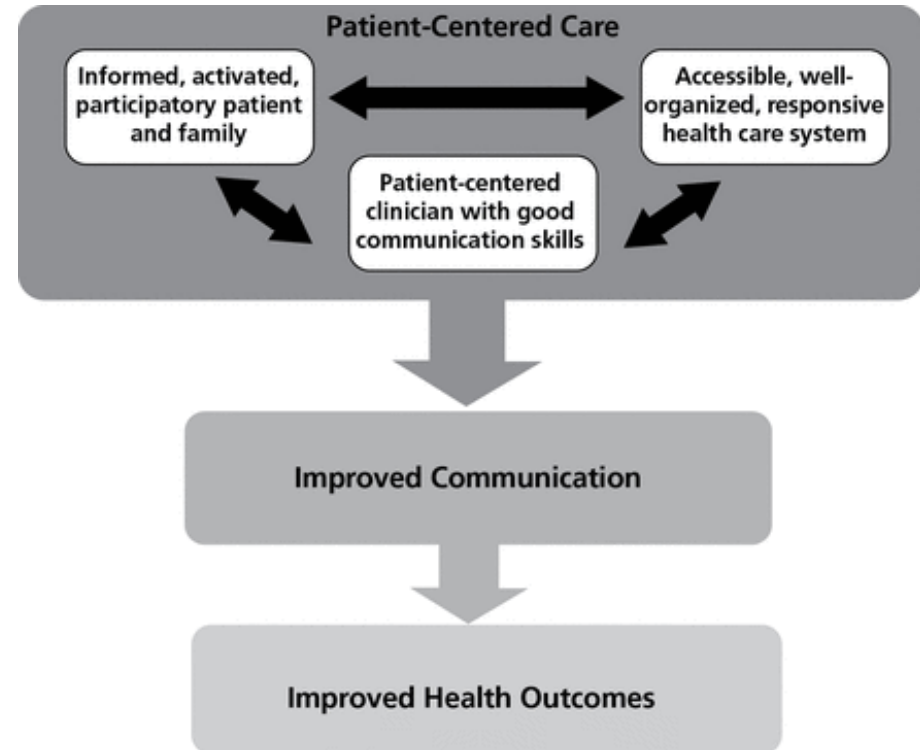
“The development of cancer services should be patient centred and should take account of patients', families' and carers' views and preferences as well as those of professionals involved in cancer care.

Individuals' perceptions of their needs may differ from those of the professional.

Good communication between professionals and patients is especially important.”

Expert Advisory Group on Cancer, 1995

USA 2015



Abrahams et al. CCR 2015; 21, 2263

The key features of “Patient Centred Care”

- **Patient centred care requires excellent quality diagnosis and treatment to achieve the best possible outcomes for patients in terms of survival, quality of life and patient experience**
- **The best clinical options are identified, preferably by a specialised multidisciplinary team**
- **Options are considered with patients, their families and carers and decisions take account of their views and preferences as well as those of the professionals**
- **Good communication is essential and the decisions are shared**

The tools we need to promote Patient Centred Care

- **Clear policy**
- **Shared expectations with patients**
- **Initiatives which are “co-produced” by patients and professionals**
- **Excellence in communication and training**
- **Modern health informatics**
- **Commissioning and management models**
- **Patient engagement (involvement, influence and impact)**
- **Patient empowerment**
- **Measuring Patient Reported Outcomes in clinical practice, clinical research and in population studies**

Cancer Research UK Psychosocial and Clinical Practice Research Group

1995

To evaluate quality of life and psychosocial morbidity in

- clinical practice
- clinical trials
- populations and health services

using novel technology to overcome logistic barriers

(NHS R&D, Selby, Cull, Gould and Forman)

I still enjoy the things I used to enjoy

Definitely as much

1

Not quite as much

Only a little

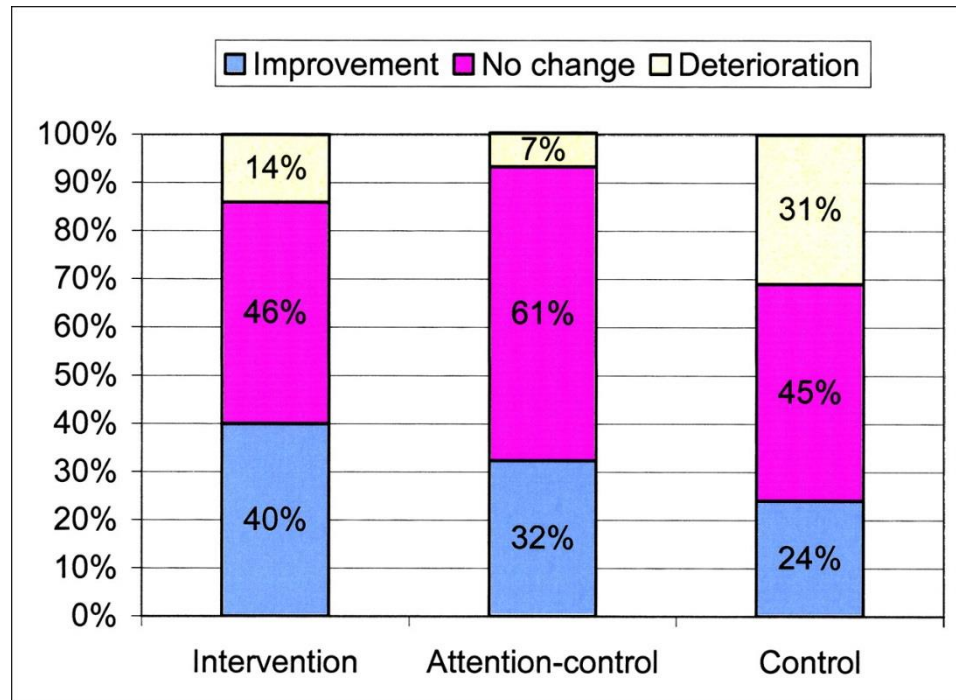
Hardly at all



Clinical Practice (2004)

Does measurement of PROMs with feedback to clinicians, improve outcomes?

Measuring HRQL on EORTC QLQ-C30 and HADS on touchscreens in clinic and informing clinicians



Outcomes were patient HRQL on FACT-G, communication and management

Proportions of patients showing clinically meaningful improvement, no change, or deterioration in Functional Assessment of Cancer-General (FACT-G) score after three encounters

Measuring quality of life in routine oncology practice improves communication and patient well-being: a randomized controlled trial. Galina Velikova, Laura Booth, Adam Smith, Paul Brown, Pamela Lynch, Julia Brown, Peter Selby. JCO 2004; 4, 714

Clinical Practice and Research

Is there a consensus about the value of PROMs in practice after some 25 RCTs Prof Valderas will discuss

Chen et al (2013): ***“Despite the existence of significant gaps in the evidence-base, there is growing evidence in support of routine PRO collection in enabling better and patient-centred care in cancer settings.”***

Kotronoulas et al (2014): ***“The routine use of PROMs increases the frequency of discussion of patient outcomes during consultations. In some studies, PROMs are associated with improved symptom control, increased supportive care measures, and patient satisfaction.”***

There is a consensus the Patient Reported Outcomes and HRQL are appropriate measures in most clinical research

Population Surveys

Life After a Prostate Cancer Diagnosis , LAPCD (Glaser and Gavin, 2016)

- **60,000 PC survivors in UK**
- **Extensive Postal Survey: EQ5D, EORTC, SDI, Prostate specific questions**
- **60% response rate; 85% of NHS Trusts in England; all NHS Trusts in Wales, Scotland and Northern Ireland**

BEST PRACTICE

- Active prevention programmes (lifestyle, vaccination, public health, etc)
- Effective, well managed screening (Cervix, Breast, CRC)
- Prompt diagnosis through engaging primary care and public awareness
- Patient involvement with genuine influence and impact
- Prompt access to best care
 - Surgery
 - Radiotherapy
 - Chemotherapy
 - Biological therapy
 - Interventional radiology
 - Psychosocial and survivorship care
 - Supportive and palliative care at all stages
- Proactive approaches to access disadvantaged groups
- Intensification of Research and Innovation
- **Measurement of outcomes drives improvements**
- **Quality of life, patient experience are vitally important outcomes to measure**

***Patient Centred, Specialised and
Integrated Multidisciplinary Care Teams***

BEST PRACTICE

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*Patient Centred, Specialised and
Integrated Multidisciplinary Care Teams*

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Overview of Quality of Life and Psychosocial Research

Giant leaps forward?? The value of measuring HRQL/PROMS in:

- Practice – see this afternoon
- Trials – yes
- Population surveys – yes
- Whole healthcare evaluation
 - Prof Velikova will discuss this afternoon

Lesson 5

*HRQL measurement drove the development of
patient centred care and its formal identification*