

EORTC QoL Group

-- 25 Years --

„The History“

Paris, 5th May 2006

Henning Flechtner, Cologne - Germany

1985 in Regensburg

A first glance ...

7th EORTC Quality of Life Workshop, 10-12 Oct 1985

Regensburg, Germany (Friedrich von Bültzingslöwen)

Meeting structure (2 1/2 days): sub groups, plenary

8th WORKSHOP in Regensburg, Germany

October 10-12, 1985.

PROGRAM

Thursday, 10th October:

- | | |
|--------------------|---|
| 09.00-09.15 | Opening and general information.
F. Bültzingslöwen |
| 09.15-10.15 | Membership and organization of the studygroup on Quality of Life
R. Zittoun |
| 10.15-12.00 | Meeting in the subgroups:
1. Conceptual views on quality of life (Jørn Beckmann)
2. Assessment of quality of life (Fritz van Dam)
3. Quality of life in pediatric oncology (E. Pichler)
4. Psychotherapeutic and psychosocial intervention (Gerjanne Bos)
5. The terminally ill patient (Barry Lunt) |
| 12.00-13.30 | Lunch |
| 13.30-14.30 | Subgroup meetings (cont.) |
| 14.30-15.00 | Coffee |
| 16.00-17.00 | Report from the subgroups in plenary.
Summary and discussion of research projects. |
| ----- | |
| 17.00-19.00 | Meeting in the monography-group for the following participants:
Neil Aaronson, Jørn Beckmann, Jan Bernheim, Birgitte Edlefsen
and Robert Zittoun |
| ----- | |
| 20.00- | Dinner |

Friday, 11th october:

Chairmen: Neil Aaronson, F. van Dam

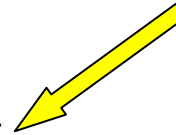
09.00-11.00	Subgroup meetings: <ul style="list-style-type: none">- conclusions- future- research- organization- activity- report
11.00-12.00	Plenary sessions: final reports of subgroup projects.
12.00-13.30	Lunch
13.30-13.45	Clinical trials. Relationship with other EORTC groups, Protocol Review Committee, Data Center. Neil Aaronson and Nicole Rotments
13.45-14.00	"Some conceptual and methodological aspects of cancer patients quality of life measurements in social environment in rural area." (* 1 *) Slobodan Lang, Miroslav Mastilica and Sanja Percac.
14.00-14.15	"Priorities in psychosocial research in cancer." (* 2 *) Jannes H. Mulder
14.15-14.30	"Quality of life - from the surgeons point of view" Hans Troidl
14.30-14.45	"Anxiety, depression and psychiatric disorders in cancer patients: assessment and risk factors." (* 3 *) D. Razavi, N. Delvaux, Ch. Farvacques
14.45-15.00	"Concurrent use of alternative and conventional cancer therapies" (* 4 *) N. van der Zouwe, I. Reurink.
15.00-15.30	Coffee
15.30-15.45	EORTC Monography on Quality of life. Jørn Beckmann
15.45-16.00	Financial report. Jan Bernheim
16.00-16.30	The Breuer Committee and our group. R. Zittoun
16.30-16.45	New president and secretary.
16.45-17.30	Next meeting and miscellaneous.
17.30-19.00	Executive meeting with the following participants: the chairmen of the subgroups, i.e. J. Beckmann, F. van Dam, E. Pichler, G. Bos, B. Lunt and furthermore Neil Aaronson, Jan Bernheim, R. Zittoun, Birgitte Edlefsen and F. Bültzingslöwen.
20.00-	Dinner

Surgical ideas on QoL (Troidl)

Saturday, 12th October.

Chairmen: J. Bernheim, R. Zittoun.

(enclosed please find papers for the abovementioned speeches).



- | | |
|-------------|--|
| 09.00-09.15 | "Comparing different methods of quality of life assessment: oral interview and mailed questionnaire." (* 5 *)
J.C.J.M. de Haes, R. Tempelaar, B.J.W. Pennink |
| 09.15-09.30 | "Quality of life in patients with non-small cell lung cancer in a randomised clinical trial." (* 6 *)
S. Ahmedzai, A. Gregor, A.J. Dorward and S.W. Banham |
| 09.30-09.45 | "Psychotherapeutic interventions for gynecologic cancer patients treated with chemotherapy: possibilities and limitations." (* 7 *)
Gerjanne Bos |
| 09.45-10.00 | "Emotionally disability in children after treatment for acute lymphatic leucemia?" (* 8 *)
Lisbeth Kristensen |
| 10.00-10.30 | Coffee |
| 10.30-10.45 | "Anti cancer service centers (ACS) in Belgium. Purposes and early realizations." (* 9 *)
D. Darms Dobois, C. Focan, K. Melan Di Portula |
| 10.45-11.00 | "Assessing social support, positive and negative elements in the social interaction of cancer patients." (* 10 *)
R. Tempelaar, B.J.W. Pennink, J.C.J.M. de Haes. |
| 11.00-11.15 | Pilotstudy on assessment of Quality of life - overview.
J. Yates (NCI) |
| 11.15-12.15 | Plenum discussion. |
| 12.15-12.30 | Closing the workshop. |

Bültzingslöwen / Zittoun

The titles marked with a number and * are all titles on papers or abstracts which are copied to you and enclosed this program.

But how and when did it all start?

1st Meeting, 1979 in Brussels

Satellite meeting at NCI-EORTC Cancer Drug
Symposium, Institute Jules Bordet,

(Maurice Staquet, Secr. Gen. EORTC)

Jan Bernheim, Frits van Dam, Robert Zittoun et al.

(15 participants - mostly physicians)

2nd Meeting, 1980, Marseille, France

EORTC Quality of Life Study Group

Chairman: Jan Bernheim

Secr.: Frits van Dam

1st EORTC Quality of Life Workshop, 22 Mai 1981,
Amsterdam, The Netherlands (Frits van Dam)

EUROPEAN ORGANIZATION FOR
RESEARCH ON TREATMENT OF
CANCER (EORTC)

Q U A L I T Y O F L I F E
Methods of Measurement and Related Areas

Proceedings of the First EORTC Quality of Life Workshop
held in Amsterdam, 22 May 1981.
Antoni van Leeuwenhoek Ziekenhuis,
The Netherlands

Published as an internal report of
the Study Group on Quality of Life

Table of contents

- I. Beckmann, J., Ditlev, G. and Blichert-Toft, M.
Quality of Life. Theoretical Considerations.
- II. Bernheim, J.L., Buyse, M.Sc.
Measurement of Quality of Life in Cancer Patients.
- III. Bindemann, S.
Management of Psychological Stress in Cancer patients:
An alternative approach.
- IV. Lang, S., Nola, P., Mastilica, M. and Bantić, Z.
Quality of Life Among Women after Mastectomy.
- V. Ledure, G., Souris, M., Bernheim, J.
Control Study of Anamnestic Comparative Self Assessment:
(ACSA)
- VI. Linssen, A.C.G., Hanewald, G.J.F.P., van Dam, F.S.A.M. and van Beek-Couzijn, A.
The development of the 'complaint questionnaire' at the Netherlands
Cancer Institute.
- VII. Maggioni, C.
A Psycho-Analytic Analysis in a Gynaecological Oncology
Department. A hypothesis of questionnaire evaluating Quality of Life
- VIII. Priestman, T.J., Baum, M., Priestman, S.
The Quality of Life in Breast Cancer Patients.
- IX. Raimbault, E., Cludy, L.
Evaluating the Quality of Life of Cancer Patients: a critical survey
- X. Staps, T.
One Aspects of the Patient's Quality of Life: The relation with
his doctor.

2nd EORTC Quality of Life Workshop, 13.-14. November 1981,
Copenhagen, Denmark (Joern Beckman)

3rd EORTC Quality of Life Workshop, 1982
Paris Hotel Dieu, France (Robert Zittoun)

4th EORTC Quality of Life Workshop, 1983
Birmingham, UK (Priestman, McGuire)

Chairman: Robert Zittoun Sec.: Joern Beckman

5th EORTC Quality of Life Workshop, 1983/84
Milano, Italy (???)

Jimmie Holland & Jan Stjernsward *"Scientific Masturbation"*

6th EORTC Quality of Life Workshop, October 1984
Zürich, Switzerland (Chrisoph Hürny)

7th EORTC Quality of Life Workshop, 10-12 October 1985
Regensburg, Germany (Friedrich von Bültzingslöwen)

Meeting structure (2 1/2 days): sub groups, plenary

Membership Fees (200.- DK)

Initiative for ESPO (Zittoun/Beckman)

Surgical ideas on QoL (Troidl)

8th Workshop, 9-11 October 1986, Gothenberg, Sweden

Predominance of Assessment – Appointment of National Coordinators

1st Field Study "EORTC Protocol 15861"

Chairman: Sam Ahmedzai Secr.: Gerjanne Bos

1st EORTC Quality of Life Newsletter, December 1986 (3 issues)

Interim meeting, 9-10 April 1987, Paris

9th Annual Meeting, 10-13 September 1987, Seamill Hydro, Scotland

1st ESPO Meeting at ECCO Conference, 1987, Madrid

President: Robert Zittoun Vice Pres.: Joern Beckman

EORTC Monograph on Quality of Life, Raven Press, New York

(Eds. N. Aaronson & J. Beckmann), Feb 1987

Interim meeting, 21-22 April 1988, Paris

Report on Protocol 15861 (Lung Cancer):

Development of a core quality of life questionnaire
for use in cancer clinical trials

Accrual (15.4.88): 373 patients, 21 institutions, 15 countries

10th Annual Meeting, 20-21 October 1988, Leiden, The Netherlands

Boat Tour to Gerjanne Bos' House

10th EORTC-QL

Leiden-Leiderdorp
october 20th 1988

Kirr Royal

Macon-Lugny 1986

Bourgogne pinot
noir 1985

Wine was sponsored
by
I.C.I.-Farma

menu

- Salade de poisson
hollandaise

- Consommé aux
fines herbes

- Choix de; pintade
au sauce mango
ou
saumon grillé

- Choix de; fromage
ou
crêpe Suzette

Interim meeting, 28-29 April 1989, Paris

11th Annual Meeting, 2-4 November 1989, Munich, Germany

Project Groups: Core Questionnaire (Aaronson)

Bone Marrow Transplantation (Zittoun)

Training Program Psychosocial Skills (Delvaux)

26-27 April 1990, Paris

Start Liaison Committee

12th Annual Meeting, 16-17 November 1990, Paris

Project Groups: Core Questionnaire (Aaronson)

Module Development (Cull)

Liaison proposal: 2 per. /EORTC Group

26-27 April 1991, Paris

13th Annual Meeting, 22-23 November 1991, Leicester

Project Group: QoL Children (Watson/Flechtner)

Chairman: Stein Kaasa Secr.: Ann Cull

Aaronson N.K., Ahmedzai S., Bullinger M., Crabeels D., Estapè J., Filiberti A., Flechtner H., Frick U., Hürny Ch., Kaasa S., Klee M., Mastilica M., Osoba D., Pfausler B., Razavi D., Rofo P.B.C., Schraub S., Sullivan M., Takeda F. for the EORTC Study Group on Quality of Life. The EORTC Core Quality-of-Life Questionnaire: Interim Results of an International Field Study in: Osoba, D. (Hrsg.): Effect of Cancer on Quality of Life, 185-203. Boca Raton, Boston, Ann Arbor & London, CRC Press, Inc., 1991

23-25 April 1992, Paris

Guidelines for Module Development (Sprangers, Cull)

14th Annual Meeting, 26-28 November 1992, Brussels

Distribution Policy for QLQ C30 (academic users, industry)

List of National Coordinators

First Manual for QLQ C30 (scoring algorithm)

Module development (Breast, H&N, Colorectal, Prostate) - Reviews

Publication 2nd Field Study

(rejected by JCO: not appropriate for readers – submitted JNCI)

Aaronson N.K., Ahmedzai S., Bergman B., Bullinger M., Cull A., Duez N.J., Filiberti A., Flechtner H., Fleishman S.B., de Haes J.C.J.M., Kaasa S., Klee M., Osoba D., Razavi D., Roife P., Schraub S., Sneeuw K., Sullivan M., Takeda F. for the European Organisation for Research and Treatment of Cancer Study Group on Quality of Life. The European Organisation for Research and Treatment of Cancer QLQ-C30: A Quality-of-Life Instrument for Use in International Clinical Trials in Oncology. J Natl Cancer I, 85(5), 365-376, 1993

22-24 April 1993, Paris (*last time at Hotel Dieu*)

Liaison proposal: mutual liaison officers

15th Annual Meeting, 25-27 November 1993, Edinburgh

Translation procedures

New Project Groups: Palliative Care

21-23 April 1994, Brussels

16th Annual Meeting, 24-26 November 1994, Trondheim

Quality of Life Unit Data Center (Gwendoline Kiebert appointed)

Exec Com: Chair/Secr., Aaronson, Ahmedzai, Sullivan, de Haes,

Osoba corresponding member NCIC

27-28 April 1995, Warsaw, Poland

Project Groups: Statisticians (Machin), Liaison (de Haes)

Palliative Care (Ahmedzai)

Module Development (Sprangers)

17th Annual Meeting, 25-26 November 1995, Copenhagen

25-27 April 1996, Pamplona, Spain

Scoring Manual, EORTC QLQ C30 Atlas of Norms

18th Annual Meeting, 21-23 November 1996, Brussels, Belgium

Chair: Ann Cull

Secr.: Mogens Groenvold

24-26 April 1997, Besancon, France

19th Annual Meeting, 20-22 November 1997, Istanbul, Turkey

23-25 April 1998, London

EORTC Pain & Symptom Control Group (Ahmedzai)

Quality of Life Unit (Andrew Bottomley appointed)

20th Annual Meeting, 15-17 October 1998, Brussels, Belgium

Formal Reports & Minutes

22-24 April 1999, Paris, France
21st Annual Meeting, 25-27 November 1999, London
Chair: Peter Fayers Secr.: Teresa Young

4-6 May 2000, Oslo, Norway
22nd Annual Meeting, 16-18 November 2000, Edinburgh, UK
*Revision Liaison Function - Joint Scientific Committee
Central Liaison Support at DC*

26-28 April 2001, Ulm, Germany
23rd Annual Meeting, 22-24 November 2001, Brussels, Belgium
2nd Edition EORTC Quality of Life Newsletter, November 2001

25-26 April 2002, Paris, France
24th Annual Meeting, 21-22 November 2002, London, UK

1-3 May 2003, Graz, Austria

Translation Committee

25th Annual Meeting, 20-21 November 2003, Rome, Italy

Dissolution JSC (Liaison Committee)

Chair: Jane Blazeby Secr.: Teresa Young

23-24 April 2004, EGAM Meeting, Brussels, Belgium

26th Annual Meeting, 18-20 November 2004, Freiburg, Germany

16-18 March 2005, EGAM II Meeting, Brussels, Belgium

27th Annual Meeting, 24-26 November 2005, Copenhagen, Denmark

Chair: Neil Aaonson Secr.: Joy Ardill/Lucca Incrocci

25th Anniversary Meeting, 5th May 2006, Paris, France

!!49th Meeting!!

What is then the correct history?

1st Meeting, 1979, Brussels

2nd Meeting, 1980, Marseille, France

1st EORTC QoL Workshop, 22 Mai 1981, Amsterdam, The Netherlands

2nd EORTC QoL Workshop, 13.-14. Nov 1981, Copenhagen, Denmark

3rd EORTC QoL Workshop, 1982, Paris Hotel Dieu, France

4th EORTC QoL Workshop, 1983, Birmingham, UK

5th EORTC QoL Workshop, 1983/84, Milano, Italy

6th EORTC QoL Workshop, October 1984, Zürich, Switzerland

7th EORTC QoL Workshop, 10-12 Oct 1985, Regensburg, Germany

8th EORTC QoL Workshop, 9-11 October 1986, Gothenberg, Sweden

Interim meeting, 9-10 April 1987, Paris

9th Annual Meeting, 10-13 September 1987, Seamill Hydro, Scotland

Interim meeting, 21-22 April 1988, Paris

10th Annual Meeting, 20-21 October 1988, Leiden, The Netherlands

Interim meeting, 28-29 April 1989, Paris

11th Annual Meeting, 2-4 November 1989, Munich, Germany

What is then the correct history?

My proposal.....

1st Meeting, 1979, Brussels – pre EORTC

2nd Meeting, 1980, Marseille, France – pre EORTC

1st Annual Meeting, 22 Mai 1981, Amsterdam, The Netherlands

Interim Workshop, 13.-14. November 1981, Copenhagen, Denmark

2nd Annual Meeting, 1982, Paris Hotel Dieu, France

3rd Annual Meeting, 1983, Birmingham, UK

Interim Workshop, 1983/84, Milano, Italy

4th Annual Meeting, October 1984, Zürich, Switzerland

5th Annual Meeting, 10-12 October 1985, Regensburg, Germany

6th Annual Meeting, 9-11 October 1986, Gothenberg, Sweden

Interim meeting, 9-10 April 1987, Paris

7th Annual Meeting, 10-13 September 1987, Seamill Hydro, Scotland

Interim meeting, 21-22 April 1988, Paris

8th Annual Meeting, 20-21 October 1988, Leiden, The Netherlands

Interim meeting, 28-29 April 1989, Paris

9th Annual Meeting, 2-4 November 1989, Munich, Germany

26-27 April 1990, Paris

10th Annual Meeting, 16-17 November 1990, Paris

26-27 April 1991, Paris

11th Annual Meeting, 22-23 November 1991, Leicester

23-25 April 1992, Paris

12th Annual Meeting, 26-28 November 1992, Brussels

22-24 April 1993, Paris

13th Annual Meeting, 25-27 November 1993, Edinburgh

21-23 April 1994, Brussels

14th Annual Meeting, 24-26 November 1994, Trondheim

27-28 April 1995, Warsaw, Poland

15th Annual Meeting, 25-26 November 1995, Copenhagen

25-27 April 1996, Pamplona, Spain

16th Annual Meeting, 21-23 November 1996, Brussels, Belgium

24-26 April 1997, Besancon, France

17th Annual Meeting, 20-22 November 1997, Istanbul, Turkey

23-25 April 1998, London

18th Annual Meeting, 15-17 October 1998, Brussels, Belgium

22-24 April 1999, Paris, France

19th Annual Meeting, 25-27 November 1999, London

4-6 May 2000, Oslo, Norway

20th Annual Meeting, 16-18 November 2000, Edinburgh, UK

26-28 April 2001, Ulm, Germany

21st Annual Meeting, 22-24 November 2001, Brussels, Belgium

25-26 April 2002, Paris, France

22nd Annual Meeting, 21-22 November 2002, London, UK

1-3 May 2003, Graz, Austria

23rd Annual Meeting, 20-21 November 2003, Rome, Italy

23-24 April 2004, EGAM I Meeting, Brussels, Belgium

24th Annual Meeting, 18-20 November 2004, Freiburg, Germany

16-18 March 2005, EGAM II Meeting, Brussels, Belgium

25th Annual Meeting, 24-26 November 2005, Copenhagen, Denmark

EORTC Quality of Life Group

25th Anniversaries

1979 – 2004

1981 – 2006

Anniversary Meeting – 25 years QLG (1981-2006)

5th May 2006, Paris, France