

International Society for Quality of Life Research
 Conference on Patient Reported Outcomes in Clinical
 Practice

24 – 26 June 2007

“Patient centred, self reported information in clinical
 practice”

- some closing comments and a positive perspective

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Patient centred, self reported information in
 clinical practice

- a very welcome and timely conference
- important contributions to
 - conceptual frameworks
 - measurements
 - study design and analysis
 - technologies and logistics
 - insights into implementation
 - challenges
- positive/negative perspectives

Patient centred, self reported information in
 clinical practice

A personal perspective

- there is a **NEED** for PCSR information in practice
- it can increase **DISCOVERY** of the relevant issues
- it is now **LOGISTICALLY** possible to collect and manage the data
- its use **MAY IMPROVE IMPORTANT OUTCOMES** in some settings
- we are **NOT YET VERY GOOD** at collecting or using the data

Patient centred, self reported information in
 clinical practice

Challenges

- clear conceptual frameworks
- what to collect and when
- how to train clinicians
- how to adapt healthcare systems
- how to change the culture in healthcare
- how to **ENHANCE** (not replace) the interactions between patients, carers, healthcare professionals and healthcare systems

Patient centred, self reported information in
 clinical practice

NEED

- only one third of patients express “real” satisfaction with care
- discontinuities in care
- underestimates of patient centred issues (trials and practice)—Fallowfield et al

Patient centred, self reported information in
 clinical practice

DISCOVERY

	114 Patients reporting on QLQ C30 moderate problems	% in notes
Fatigue	34	29
Pain	24	58
N & V	35	14
Dysnoea	18	56
Sleep	27	7
Appetite	18	39
Constipation	13	8
Diarrhoea	4	25
Finance	14	7

JCO 2002

Patient centred, self reported information in clinical practice

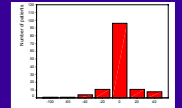
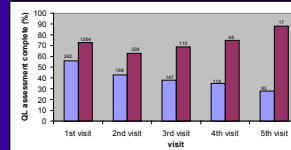
LOGISTICS—buy a lottery ticket!!

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)

Logistics- technology

- Touch-screen data collection
- Comparison TS vs paper (J Clin Oncol, 1999)
- Patient compliance with regular QOL collection (J Clin Oncol, 2003)



Patient centred, self reported information in clinical practice

IMPROVE IMPORTANT OUTCOMES

- ✦ Improve communications
- ✦ Generally negative results in psychiatry –depression outcomes
- ✦ Oncology—two important positives
- ✦ Overall still too few conclusive well designed studies

Health-Related Quality of Life Assessments and Patient-Physician Communication

Detmar, Aaronson et al, 2002

Randomised Trial: 214 patients / 10 physicians

EORTC QLQ-C30 for 3 visits with cross-over

In use of QLQ-C30 led to:

- more HRQL issues discussed
- more health problems identified
- support from patients and staff
- no change in QL (on SF 36)
- improvements in mental health (p = .04) and roles (.05)

Health-Related Quality of Life Assessments and Patient-Physician Communication

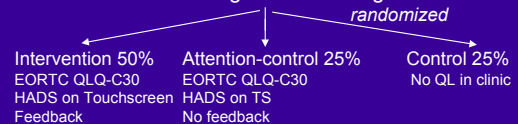
Detmar, Aaronson et al, 2002

Improvements in QL on SF 36 (0.5 SD unit)

	Emotional function	Role function
Control	30%	11%
Intervention	43%	22%
	p = .04	p = .05

Randomised Trial - Study Design

Patients starting chemo-/biological treatment



Process outcomes: tape-recording of consultations – content analysis

Patient outcomes

FACT-G (QOL Questionnaire)
Continuity & Co-ordination of Care
Satisfaction

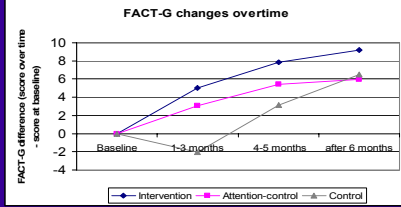


@ baseline
post 3 interventions
@ 4 months
@ 6 months

Results Patient well-being

Changes in FACT-G scores over time

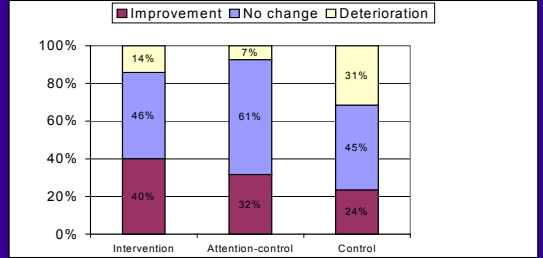
Variables in order entered into model	Estimate of intervention effects	p-value
Baseline FACT-G	0.02	<0.001
Performance status 0 vs 3	11.75	0.01
1 vs 3	10.20	0.02
2 vs 3	11.17	0.01
Time	0.03	0.03
Study arm		
Interv. vs Control	-8.01	0.006
Interv. vs Attn-Contr	0.76	0.80
Attn-Contr vs Control	-8.77	0.01



Results- Patient well-being Proportion of patients with improvement or deterioration in FACT-G scores

NNT = 4.2

Interv vs Attn-contr + Contr p=0.007, Interv + Attn-contr vs Control p=0.003



Further analysis of communication and decision making

Symptoms

- Providing QOL data lead to more consistent discussion of
 - Insomnia (p=0.003)
 - Dyspnoea (p=0.03)
- Symptoms more often raised by doctor
- Discussion of common symptoms depended mainly on whether the problem was raised at baseline
 - Pain, fatigue, nausea, appetite

Functioning

- Providing QOL data lead to more consistent discussion of
 - Physical function (p=0.006)
 - Emotional function (p=0.03)
- Not initiated by doctor
- No effect on social function

Attention-control study

Patients starting treatment n=220

randomised

Attention-control 50%
EORTC QLQ-C30
HADS on TS
No feedback

Control 50%
No QOL in clinic

Results

No significant differences in FACT-G scores were found between attention-control and control arm patients

Process outcomes: communication and decisions-making
audio-recording of consultations – content analysis

Patient outcomes

FACT-G (QOL Questionnaire)
Continuity & Co-ordination of Care
Satisfaction

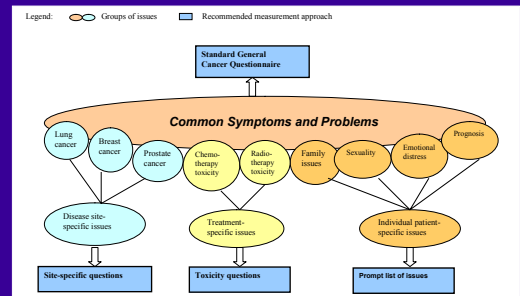
@ baseline
after 3 interventions

Focus groups—what do patients and professionals want?

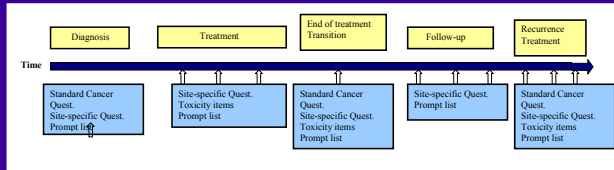
- Framework analysis
- Common symptoms and problems across cancer patients
 - General cancer questionnaire
- Disease- and treatment-specific problems
 - Site- specific items
 - Toxicity items
- Individual-specific items – Emotions, Prognosis, Sexuality
- Timing and scope of enquiry
 - Different questions at diagnosis, during treatment, during follow up

Designing and testing a new intervention

Groups of identified issues/problems in oncology practice and recommendation for their measurement



Time-based model for measurement of symptoms, functioning and QOL in daily oncology practice



Patient centred, self reported information in clinical practice

NOT YET VERY GOOD!

- Incomplete conceptual frameworks
- interventions often based on “instruments” developed for other purposes
- Limited number of rigorously designed studies
- Little influence on healthcare training or planning

Patient centred, self reported information in clinical practice

SO WHAT IS NEEDED

- CONTINUED WORK ON
 - CONCEPT
 - METHODOLOGY
 - TECHNOLOGY
 - TRAINING
 - IMPLEMENTATION
 - INFLUENCE CULTURE

Patient centred, self reported information in clinical practice

SPECIFIC AREAS FOR FUTURE WORK

- interventions—approaches that are purpose built and engage patients and healthcare workers in their development.
- Applications where impact likely to be greatest—continuity in common diseases
- service impacts—multiple outcome studies
- technologies for wide access

Patient centred, self reported information in clinical practice-conclusions

Given the still modest work on methods and interventions

and

Given the positive results in several areas



the potential for benefits for patients and healthcare systems is very substantial

the continued effort is well worthwhile

PCSR TECHNOLOGIES SHOULD BE AIMED TO ENHANCE THE INTERACTIONS BETWEEN PEOPLE - NOT TO REPLACE THEM

Preliminary results of Attention-control trial

□ No significant differences in FACT-G scores were found between attention-control and control arm patients ($p=0.57$)

□ Compatible with previous trial

