

Measuring Quality of Life in Oncology

Th. Küchler

„Referenzzentrum Lebensqualität in der Onkologie“

Department of General and Thoracic Surgery of the University
Hospital of Schleswig-Holstein, Campus Kiel

Overview of today's talk:

- **What is Quality of Life (QoL)?**
- **Why should we measure „health-related QoL“?**
- **How should we measure HRQoL?**
- **When should we measure it?**

and

- **What will we get out of it?**

Introduction

From 1998 to 2001 the “German Cancer Help” (Deutsche Krebshilfe e. V.) funded the implementation of a

“Reference-Center on Quality of Life in Oncology”

(“Referenzzentrums Lebensqualität in der Onkologie”).

The overall aim of this Project was to actively initiate and/or support research initiatives in cancer that involved assessing QoL as primary or secondary endpoints.

This novel research institute is attached to the Department of General and Thoracic Surgery, to maximize proximity to daily clinical care. Accordingly, the biggest part of research activity has been related to surgery (including adjuvant regimens).

Referenzzentrum Lebensqualität in der Onkologie (RZLQ)

Areas of expertise:

**Area 1: Quality of life research /
clinical outcomes research**

**Area 2: Psychooncology /
Psychosocial Care**

**Area 3: Quality Assurance/
Quality Management**

Core Competencies:

1

- **Planning, Implementation, Analyses, Interpretation and Presentation of "clinical outcomes studies,, with a focus on HRQoL;**
- **Methodological / statistical counselling**
- **Design and development of tools**
- **Teaching**

2

- **Psychooncology, psychotherapy, psychosocial care programs, supervision**
- **Health Services Research (with focus on psychosocial interventions)**
- **Teaching**

3

- **Planning, Implementation, Analyses, Interpretation and Presentation of patient' satisfaction assessment**
- **complaints management**
- **Teaching**

Back to the initial question:

**What is
„Quality of Life“?**



„Dr. Birnes here believes in the holistic approach“

Diagnosis

Treatment



Patient

Survival

Quality of Life

**„To have a ,quality of life‘
you have to be alive!“**

B. Kremer, 1994

What is Quality of Life (QoL)?

„Quality of Life“ represents a

- philosophical
- political
- economic
- social science
- and
- medical term

What is „Quality of Life“?

„...and often the same person changes his mind: if he gets sick, then it is health, and if he is well, then it is money.“

-Aristoteles-

Nikomachische Ethik

What is „Quality of Life“?

→ QoL has a completely different meaning for patients (sick people) than it has for healthy individuals;

→ the evaluation of the relative importance of different components of QoL differs greatly between individuals (sick or healthy);

Quality of Life :

There is a distinct difference between the

term,

the concept and

the „technical“ aspects of assessment

(measurement)

Die Lebensqualität auf dem Friedhof soll besser werden

UNTERLÜSS. – Der alte Teil des Friedhofs in der Gemeinde Unterlüß soll nach dem Jahre 2000 umgestaltet werden. Während eines Arbeitsgespräches im Rathaus informierte Bürgermeister Eberhard Stainer (CDU) die nichtstimmbe-

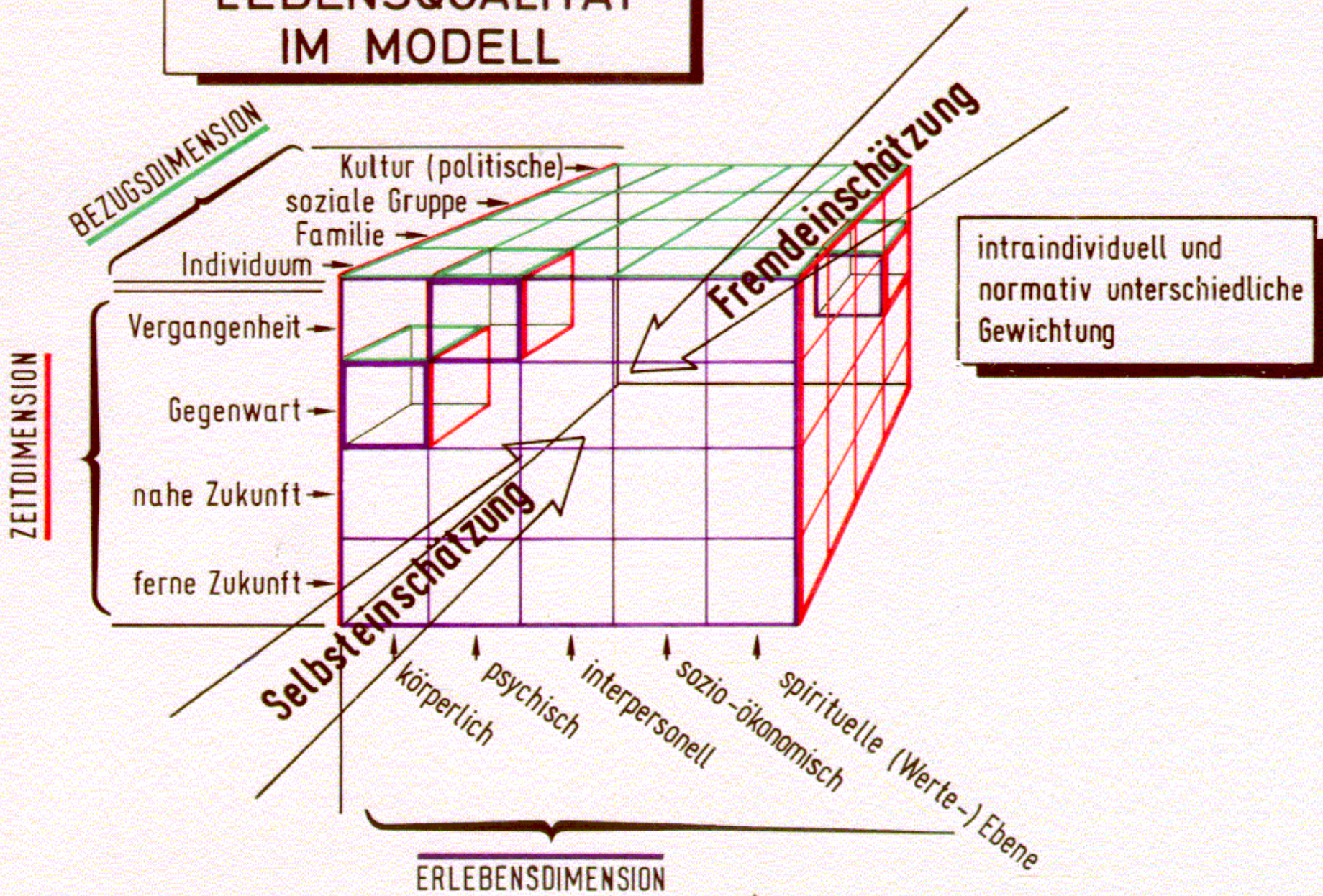
Gestaltung finden. Der Ehrenhain soll eine offene Gestaltung mit Unterpflanzung erhalten. Auch sollen die Gedenksteine hier...

Aus der Celleschen Zeitung

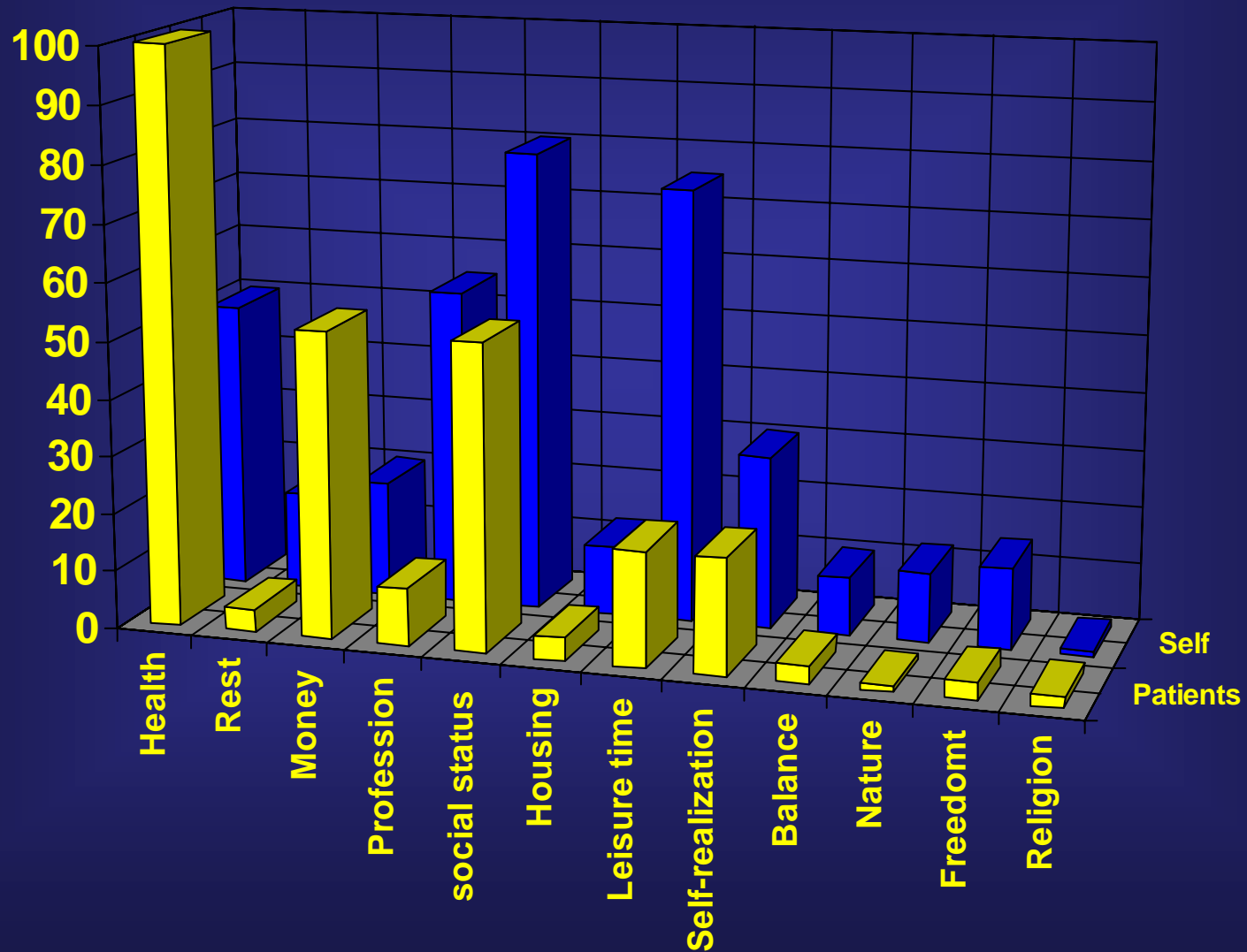
„The quality of life in our cemetery has to be improved“

(from local newspaper)

DIMENSIONEN DER "LEBENSQUALITÄT" IM MODELL



First open question to german doctors (N = 200) :
How would You personally for yourself define quality of life?
And second question:
How is QoL defined by the majority of Your patients?



Open question to Egyptian and German doctors: How would You define quality of life?



What is „Quality of Life“?

Satisfaction (with life):

Evaluation of what you have

Expectation

= Satisfaction

Hofstätter, 1986

**What is „health-related“
quality of life (HRQoL)?**

What is „health-related“ quality of life ?

„Health-related“ quality of life has a

**physical,
mental (emotional and cognitive)
interpersonal,
socioeconomic
spiritual**

Dimension.

These dimensions are „subjectively“ interrelated

How should we assess QoL?

- **Proxy Rating:** Someone who knows the patient well (enough) completes the questionnaire on behalf of the patient (i. e. health care provider, partner etc.) Note: often there is only low correlation with the patient's judgement!
- **Patient self report**
(patient reported outcomes - PROs):
Patients themselves complete the questionnaire (subjective evaluation)

How should we assess QoL?

- **generic questionnaires:** Used across populations, can compare the impact of different diseases. Disadvantage: may not reflect changes in patient's status.
- **disease specific questionnaires:** Used for specific diseases, conditions, populations and treatment regimens (i. e. pancreatic cancer, incontinence, children or elderly, surgery vs. pharmaceutical treatment). Very responsive, because they usually incorporate (specific) symptoms. Disadvantages: comparability across patient groups is difficult or impossible

Review: QoL - Questionnaires



Mostly used european instrument in oncology

Advantage:

Corequestionnaire + sitespecific modules

Mostly used north-american instrument in oncology

Advantage:

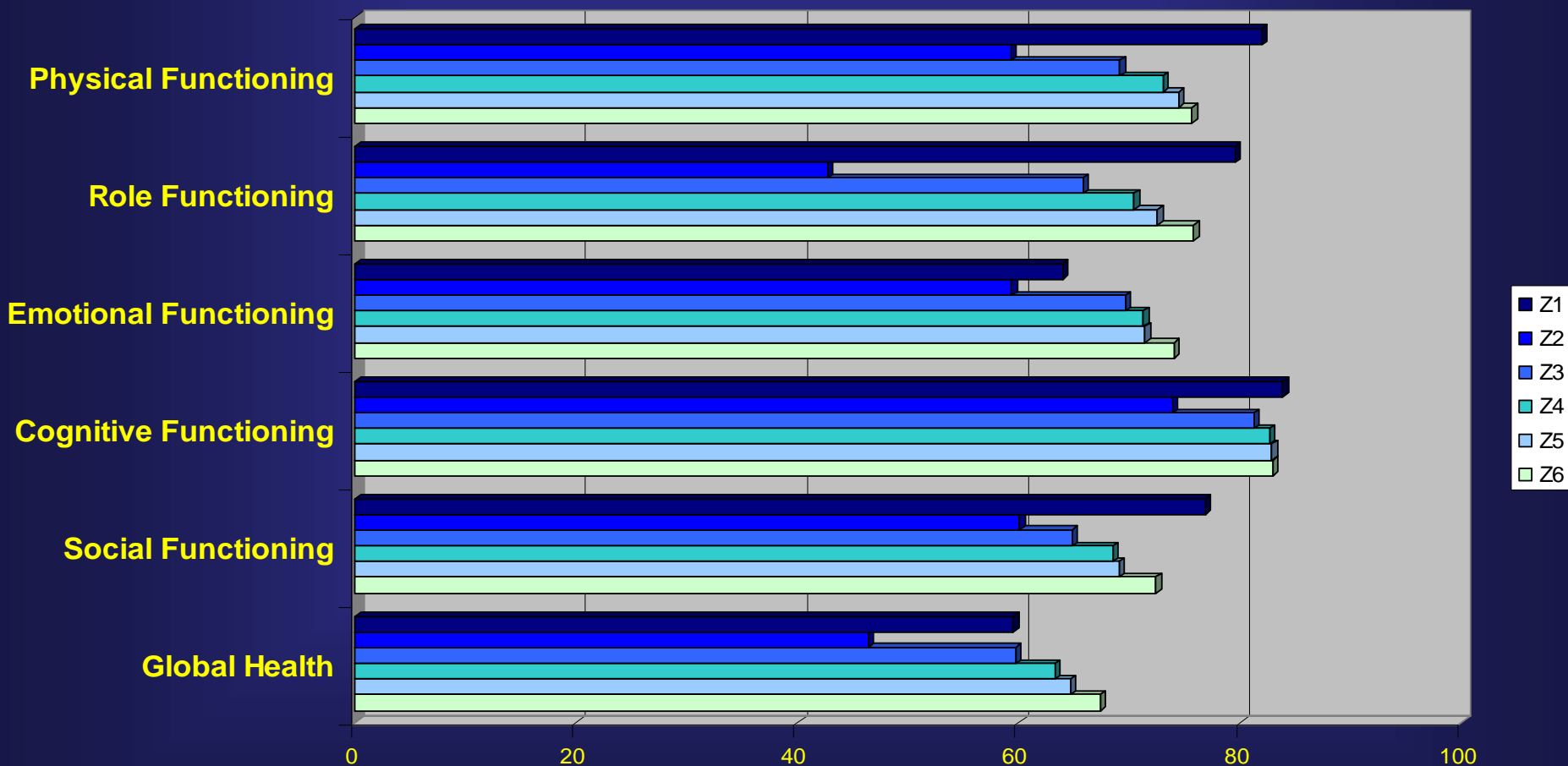
Widest collection of sitespecific modules

Mostly used for non-oncological research questions

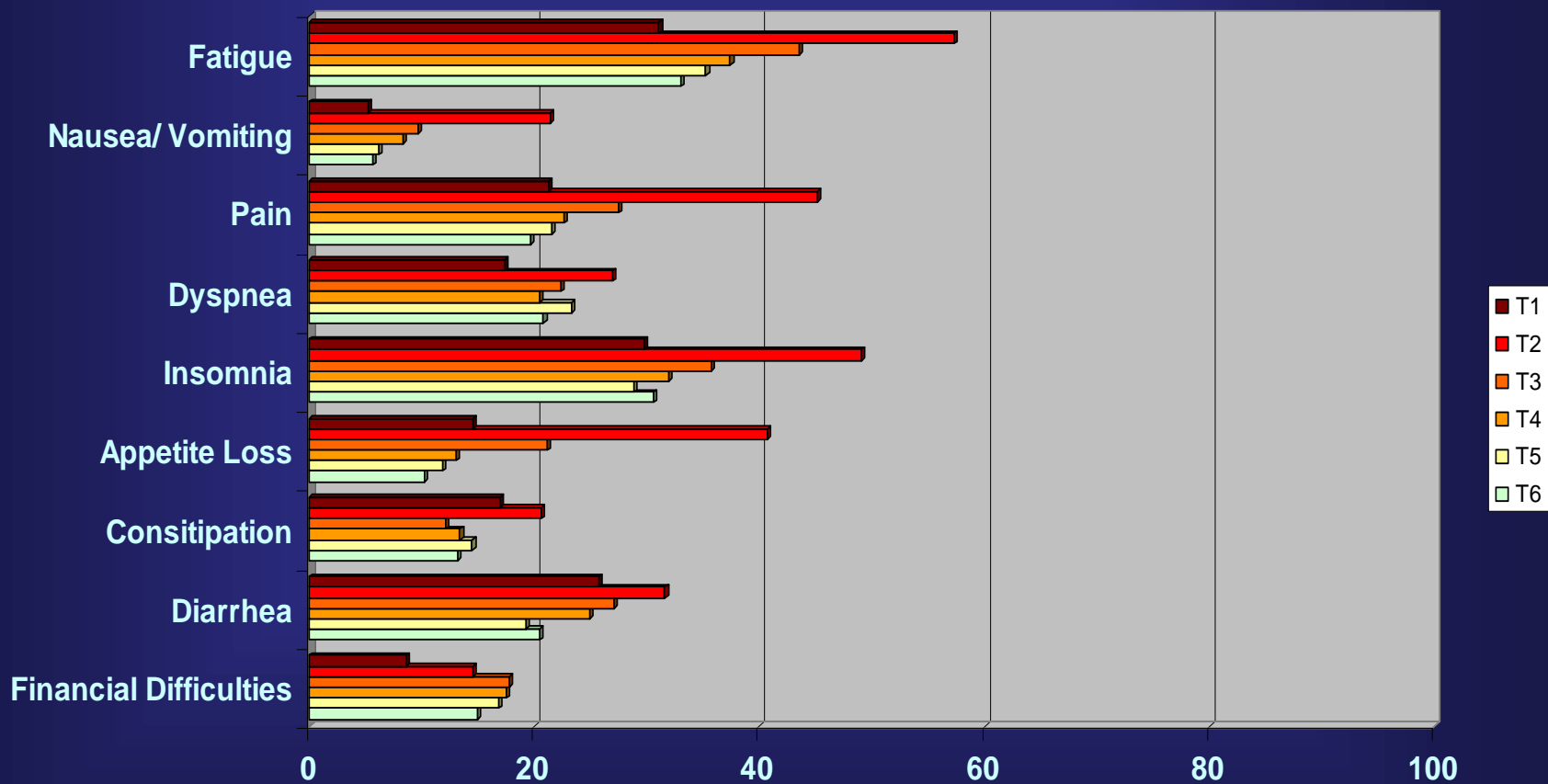
Advantage:

Norms for a variety of „healthy“ people

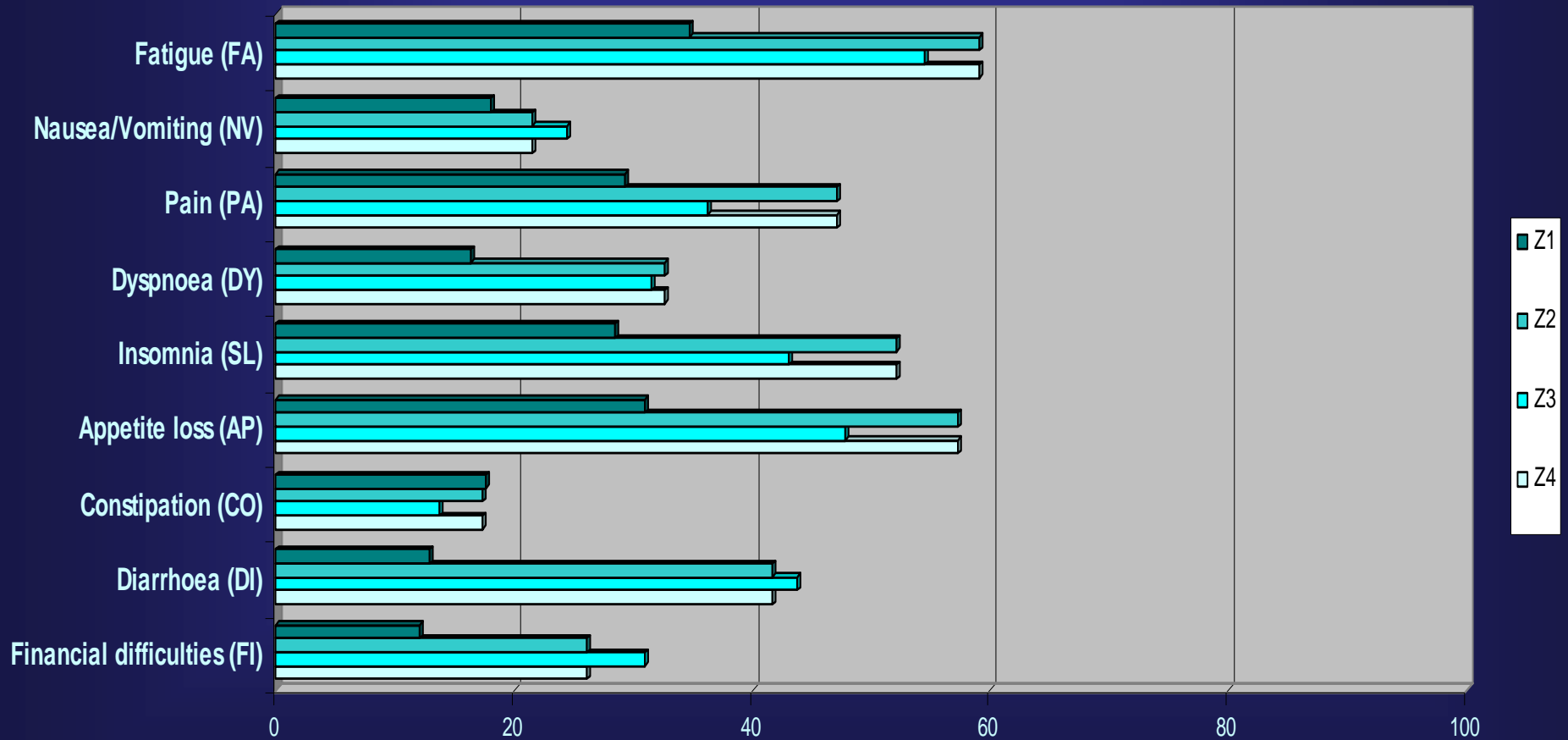
Patients with colorectal cancer (N = 368) - QoL from preoperatively to 2 years postop - EORTC QLQ-C30 Function scales



**Patients with colorectal cancer (N = 368) -
 QoL from preoperatively to 2 years postop -
 EORTC QLQ-C30 Symptom Scales**



Patients with stomach cancer (N = 238) - QoL from preoperatively to 1 years postop - EORTC QLQ-C30 Function scales (Symptomskalen)



- 1. Based on these longitudinal data it is possible to assess the outcomes of different therapies (i. e. medical, surgical, pharmaceutical...).**
- 2. Further new approaches to therapy can also be compared to standard care.**
- 3. Between 2005 and 2007, researchers in our clinic have published 16 papers in international journals with a total impact factor > 40.**

Oesophageal cancer module: EORTC QLQ – OES18

Gastric cancer module: EORTC QLQ – STO22

Oesophago-gastric cancer (QLQ-OG25)

Pancreatic cancer module: QLQ-PAN26

Primary liver cancer module: EORTC QLQ-HCC18

Pancreatic cancer module: QLQ-PAN26

**Colorectal cancer modules: EORTC QLQ-CR38 and
EORTC QLQ-CR29**

**Liver metastases from colorectal cancer: EORTC QLQ-
LMC21**

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

During the past week:

	Not at All	A Little	Quite a Bit	Very Much
31. Have you had problems eating solid foods?	1	2	3	4
32. Have you had problems eating liquidised or soft foods?				
33. Have you had problems drinking liquids?				
34. Have you had discomfort when eating?				
35. Have you had pain in your stomach area?				
36. Have you had discomfort in your stomach area?				
37. Did you have a bloated feeling in your abdomen?				
38. Have you had trouble with acid or bile coming into your mouth?				
39. Have you had acid indigestion or heartburn?				
40. Have you had trouble with belching?				
41. Have you felt full up too quickly after beginning to eat?				
42. Have you had trouble enjoying your meals?				
43. Has it taken you a long time to complete your meals?				
44. Have you had a dry mouth?				
45. Did food and drink taste different from usual?				
46. Have you had trouble with eating in front of other people?				



State of the QoL – Databank (11/2007) at the „RZLQ“

Time / Tumorsite (Diagnosis)	Lung	CoRe	LivGa	Stom	Eso	Pan	Sum	
preoperative	392	757	194	255	95	221	1914	
postoperative	307	699	132	176	81	144	1549	
3 Month post OP	458	978	211	236	111	197	2191	
6 Month post OP	372	889	196	205	101	175	1938	
12 Month post OP	274	751	154	143	72	129	1523	
24 Month post OP	184	613	110	98	39	81	1125	
Sum	1987	4687	997	1113	499	957	10240	
Different timepoints/ tumorsites	Prostate cancer	„Healthy“ controls	Other tumor sites (small numbers in subgroups like NCC)			Relatives		
	1500	1200	800			300		

Measurement properties of questionnaires

- **Reliability** : the degree to which measure is free from random error
- **Validity**: The questionnaire actually measures what it is supposed to measure.
- **Responsiveness**: the ability of a questionnaire to accurately measure change over time.
- **Practicability**: easy to use, to score, to interpret and not „costly“

Components of a good QoL - trial

1. A question that includes the population, the intervention, the comparison and the outcomes.
2. A specific study-design with a sufficient number of subjects to allow the question to be answered
3. A carefully planned and executed protocol
4. Outcome instruments with sufficient psychometric properties
5. A plan for analysis that incorporates the QoL data
6. Up-front sufficient funding

Summary I

- There is no „Goldstandard“ questionnaire to assess health related quality of life
- The choice of an appropriate questionnaire depends on the patient population, the research question and the resources of the given trial!
- In a european oncological study however the EORTC QLQ C30 is first choice because of its modular approach and ist high comparability

Summary II

- The assessment of HRQoL adds an extra dimension to the traditional outcomes related to **morbidity** and **survival**.
- In addition to a strong study protocol, it is essential to select the most appropriate instrument – one with strong psychometric properties – so you can be confident of the results.
- In pharmacological studies the systematic assessment of quality of life will become mandatory (looking at developments in the USA)



**Thank You
for Your
attention!**