

THE GERMAN PATIENT EDUCATION PROGRAM in PRIMARY SYSTEMIC VASCULITIS

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Background

- **Patient education is effective as an additional therapy ^{1,2}**
- **Guidelines of the German society of Rheumatology**
- **Systematically planned and implemented procedure**
- **Certification**
- **Standardized psychological and educational methods**

1 Langer et al. (1998) Evaluation des Patientenschulungskurses ‚Chronische Polyarthritis‘, Deutsche Rentenversicherung 3-4:239-264

2 Thieme et al. (1997) SLE-Patientenschulung. Das SLE-Patientenschulungsprogramm – Programminhalt und erste Evaluationsergebnisse. Akt Rheumatol 22:98-104

Background/Development

Needs assessment (100 patients)

- **Definition of specific learning objectives**
- **Interdisciplinary concept**
- **Physicians, nurses, psychologists, physiotherapists, dieticians**
- **Development of five structured modules**
- **Manual with slides/transparencies and information**

Background/Objectives/Hopes

Knowledge ↑

- **Disease activity ↓**
- **Side effects ↓**
- **Morbidity ↓**
- **Health-related quality of life ↑**
- **Inpatient days ↓**
- **Sick leave days ↓** → **costs ↓**

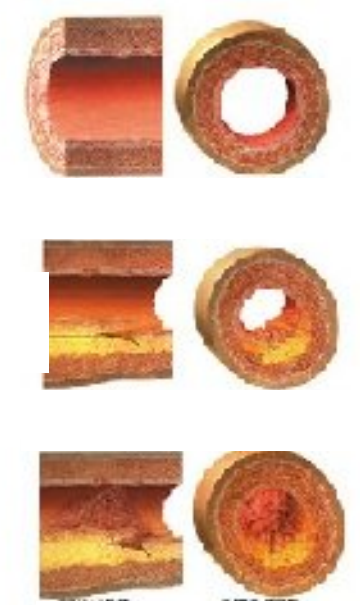
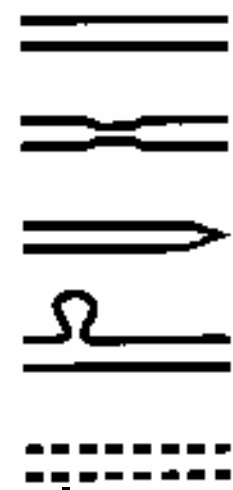
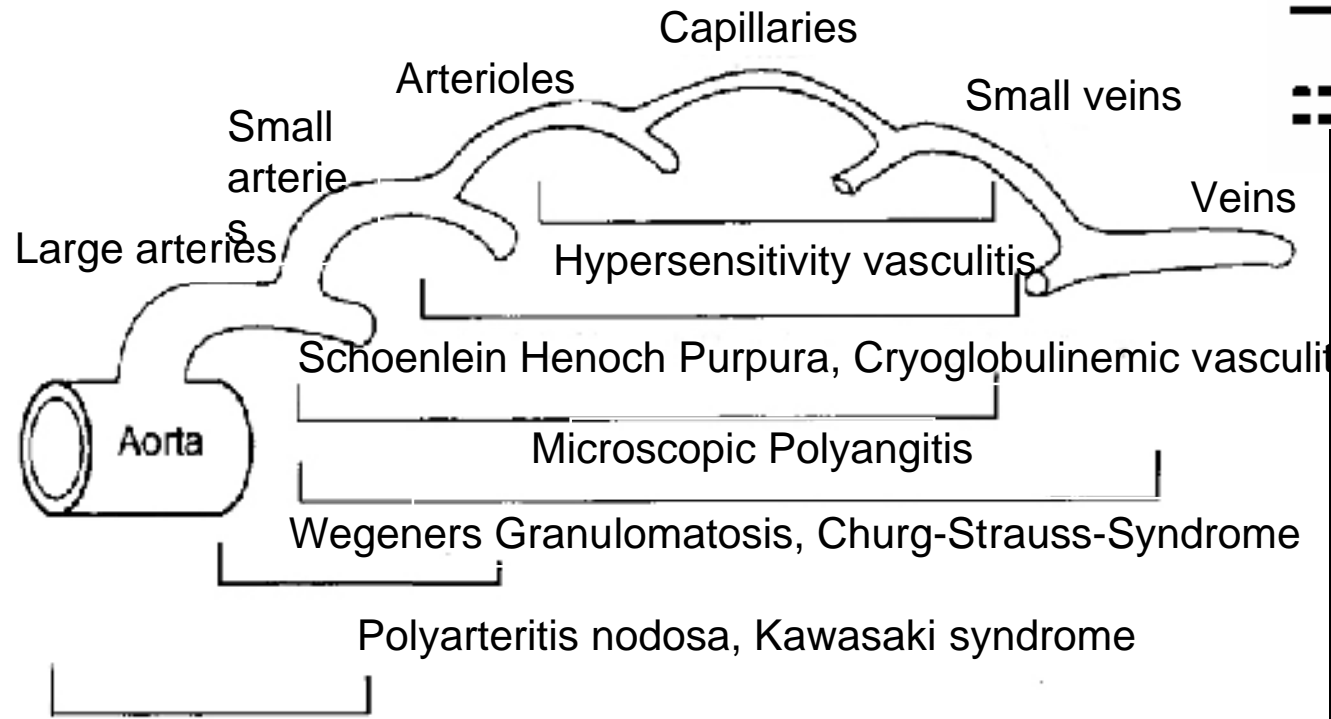
Module	Discipline	Content
1	Physician	Vasculitis, Immunology, diagnostic procedures
2	Physician/Nurse	Treatment, side effects, monitoring
3	Psychologist	Acceptance, stress, coping strategies
4	Physiotherapist	Mobility, skills for home
5	Dietician	Inflammation, Osteoporosis, reduction of side effects

Module 1 - examples

You should

- **have knowledge of your disease**
- **be a specialist on your individual vasculitis**
- **„help“ your physicians**
- **be the first to know and feel changes in your health status**
- **be attentive and observing**

Involvement of vessels



Types of vasculitis

Small vessel :

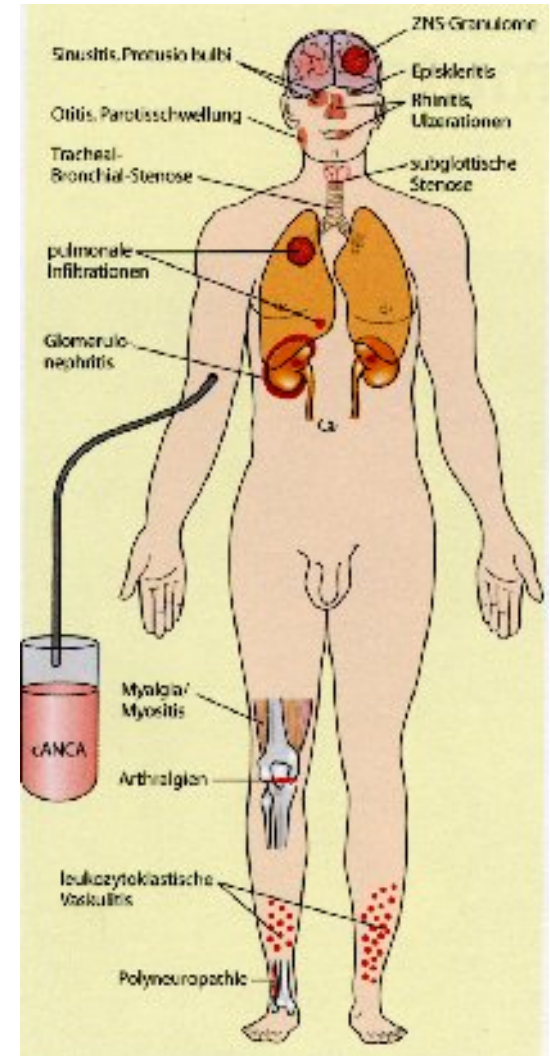
- Wegener`s Granulomatosis**
- Microscopic polyangitis**
- Churg-Strauss-Syndrom**
- Hypersensitivity vasculitis**
- Schoenlein-Henoch Purpura**

Medium size vessel:

- Polyarteritis nodosa**
- Kawasaki disease**

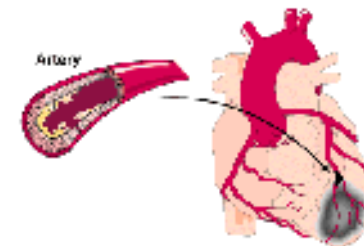
Large vessel :

- Giant cell arteritis**
- Takayasu`s arteritis**



Direct signs of vasculitis in small vessels:

- the “red eye”
- sudden loss of vision
- hearing loss
- nasal crusting, bloody nasal discharge, obstruction, sinusitis, ulcers
- skin: small red spots on the skin
- nerves: paraesthesia of feet or hand
- lungs: hemoptysis, cough, dyspnea
- kidney: hematuria
- intestine: bloody diarrhea
- heart: peri- or myocarditis



Direct signs of vasculitis

Medium size vessels:

**Central nervous system,
heart, kidney, intestinal**

Large vessels:



**severe temporal headache
swelling of the temporal artery
sudden visual loss
thrombosis**

Indirect signs of vasculitis

Constitutional symptoms:

fever

fatigue

weight loss

night sweat

reduced physical capacity

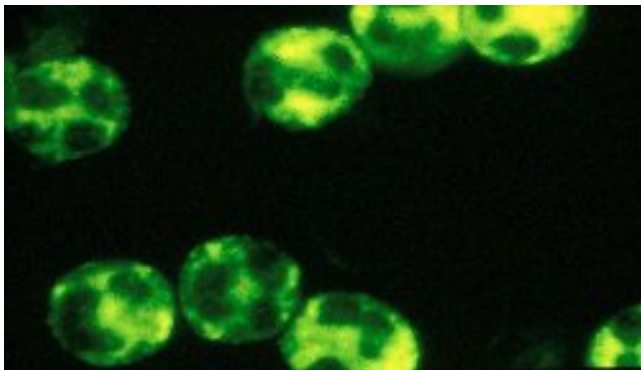


Laboratory investigations

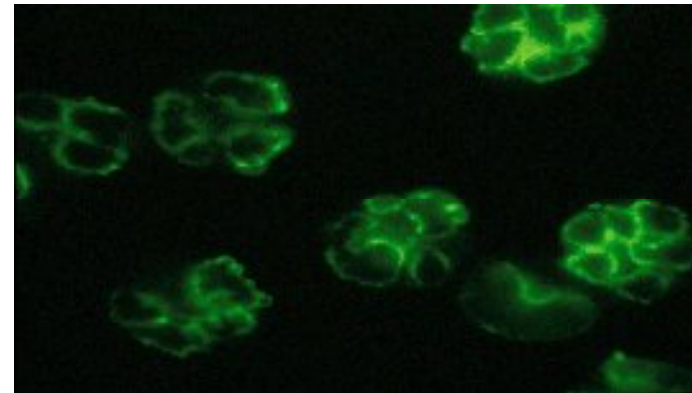
Diagnosis: to set up disease, severity, activity and extent

Follow up: determine effectiveness of therapies

Monitoring: Identification of side effects



cANCA



pANCA

Further topics module 1

- **Different types of vasculitis depending on the participants**
- **Diagnostic procedures**
- **Possible causes of vasculitis**
- **Behaviour: what can I do myself at home**
- **Monitoring of urine, weight, blood pressure**
- **Awareness**
- **Regular examinations as proposed by physician**
- **Vasculitis pass**

Module 2: Treatment

- **Goals of treatment: remission**
- **Individual treatment**
- **Standardized studies**
- **Effects**
- **Guidelines: dosage, administration, additional treatment**
- **Side effects**
- **How to cope with the side effects**
- **Monitoring**
- **Research: new therapeutic options**

Module 2: Therapy - examples

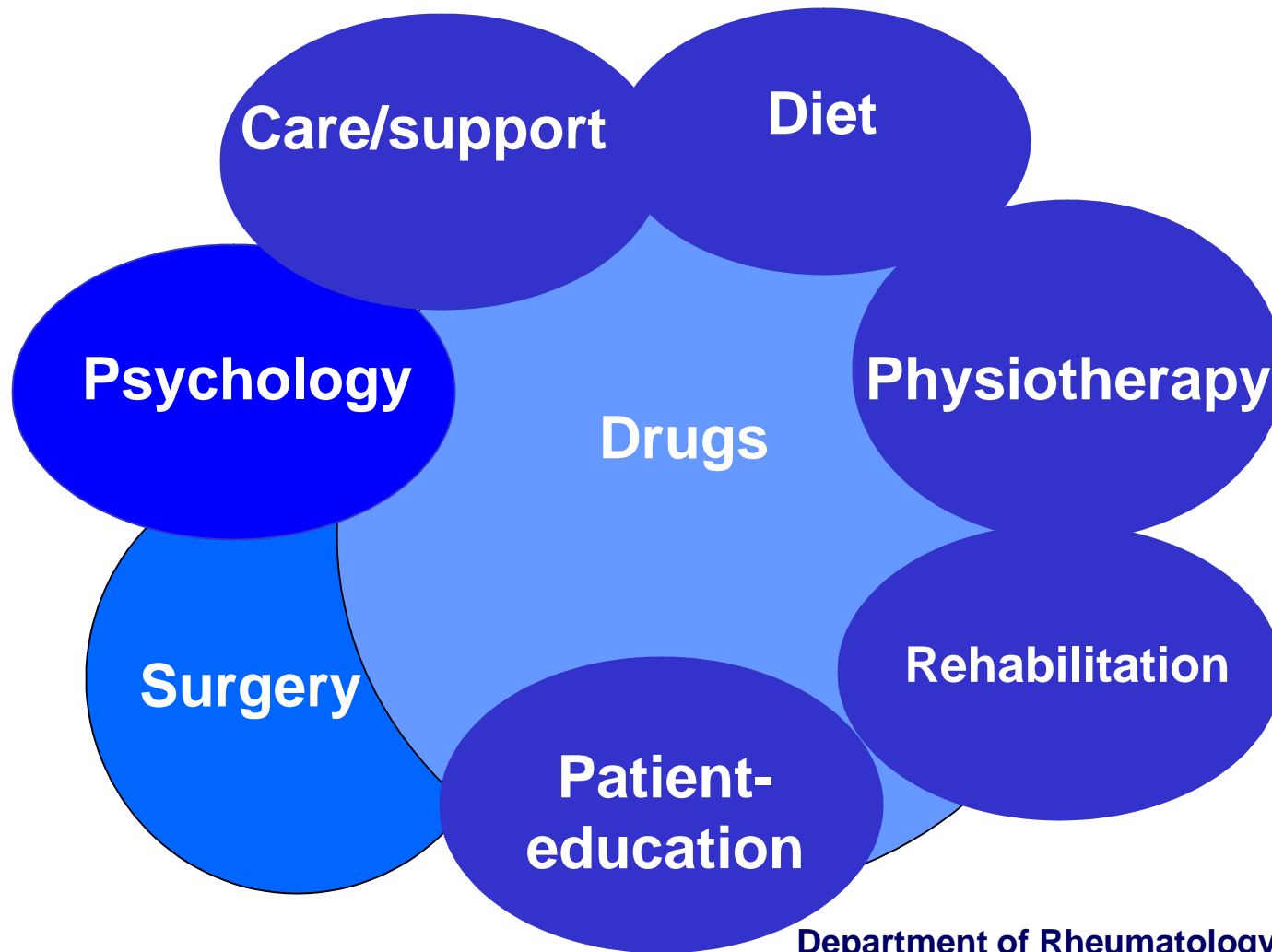
- **Corticosteroids**
- **Azathioprine** **Azasan[®], Imuran[®]**
- **Methotrexate** **Rheumatrex[®], Trexall[®]**
- **Leflunomide** **Arava[®]**
- **Cyclosporine** **Sandimmune[®], Neoral[®], Gengraf[®]**
- **Mycophenolate** **CellCept[®]**
- **Cyclophosphamide** **Cytoxan[®], Neosar[®]**
- **TNF- α –Blocker** **Remicade[®], Enbrel[®], Humira[®]**
- **Rituximab** **Rituxan[®]**

VZ



Vaskulitis-Zentrum

Module 2: Therapy – other options



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Module 3 - Psychology

- **How does stress influences disease/vasculitis**
- **Can I change my behaviour**
(relaxation techniques, social contacts, support group, conversation, information)
⇒ **change what I can change**
- **Acceptance of the disease, coping strategies**
- **Reduction of stressful events**
- **Relaxation (nature, yoga, autogenic training)**

Module 4 - Physiotherapy

- **Pain of joints, muscles, tendons, nerves, organs**
- **Influence by motion, stretching**
- **Is movement useful: improves general condition, fun**
- **Adequate sports**
- **Cardiac and pulmonary support**
- **Prevention of osteoporosis**
- **Improvement of metabolism**
- **Regular training - always individual plan**

Module 5 – Diet/Nutrition

- **Diet and autoimmune diseases**
- **Diet and inflammation**
- **Diet and therapy, e.g. corticosteroids**
- **Effects of arachidonic acid, fish oil, vitamins**
- **Unsaturated fatty acids**
- **Mediterranean diet**

Disease assessment

- **By physicians:**
 - activity: **Birmingham Vasculitis Activity Score (BVAS)**
 - extent : **Disease Extent Index (DEI)**
 - damage: **Vasculitis Damage Index (VDI)**
- **Epidemiology: Vasculitis registers**
- **By patients:**
- **Patient perspective: new research project**
- **Quality of life: e.g. Short Form 36**

Vasculitis register Schleswig-Holstein 1998-2006



2005		
n m/w	Alter*	PSV-Typ
40 (11/28)	70 (53/86)	AT
5 (2/3)	56 (30/85)	KLA
25 (15/10)	58 (30/83)	WG
5 (3/2)	63 (22/88)	CSS
4 (1/3)	74 (39/75)	MPA
14 (8/6)	7 (4/15)	HSP
1 (0/1)	84 (84)	PAN
0	0	TA
2 (1/1)	5 (4/7)	Kawasaki
13 (3/10)	66 (36/85)	UV
109 (44/64)		

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Evaluation

- **Prospective study in a pre/post design**
- **Assessment before, 4 weeks, 6, 12 and 24 months after participation**

Outcome measures:

- **Knowledge (16 questions, Score 0-45)**
- **Health-related quality of life (SF-36)**
- **Functional capacity (NRS 0-10)**
- **Self- efficacy (9 item scale, Hasenbring et al.)**
- **Socioeconomic factors**
- **Disease extent index (DEI)**

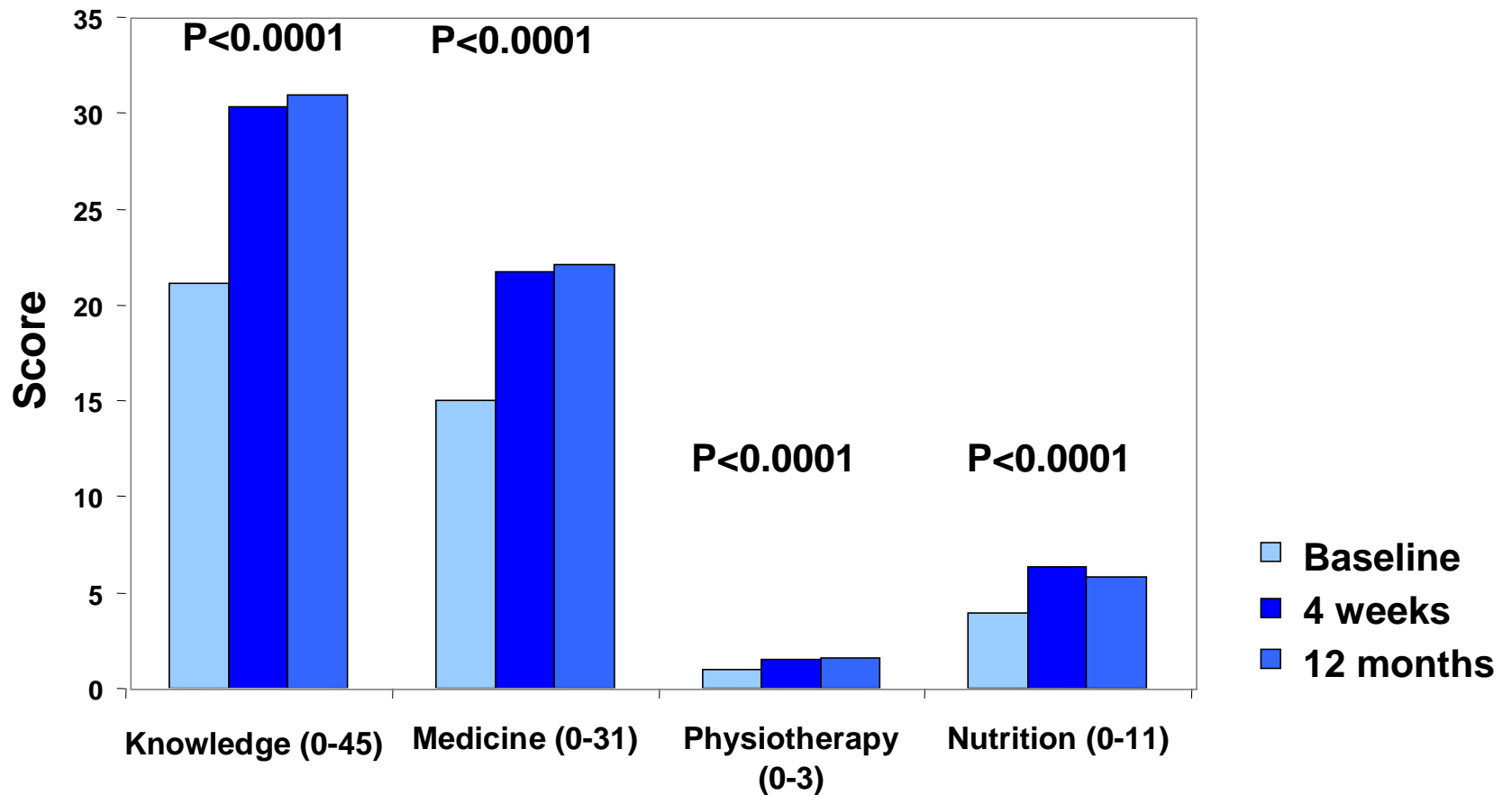
Herlyn et al (2002) Wissenschaftlich begründete Patientenschulung am Beispiel der Patienten mit primär systemischen Vaskulitiden. Z Rheumatol 61:13-20

Results: patient characteristics (baseline)

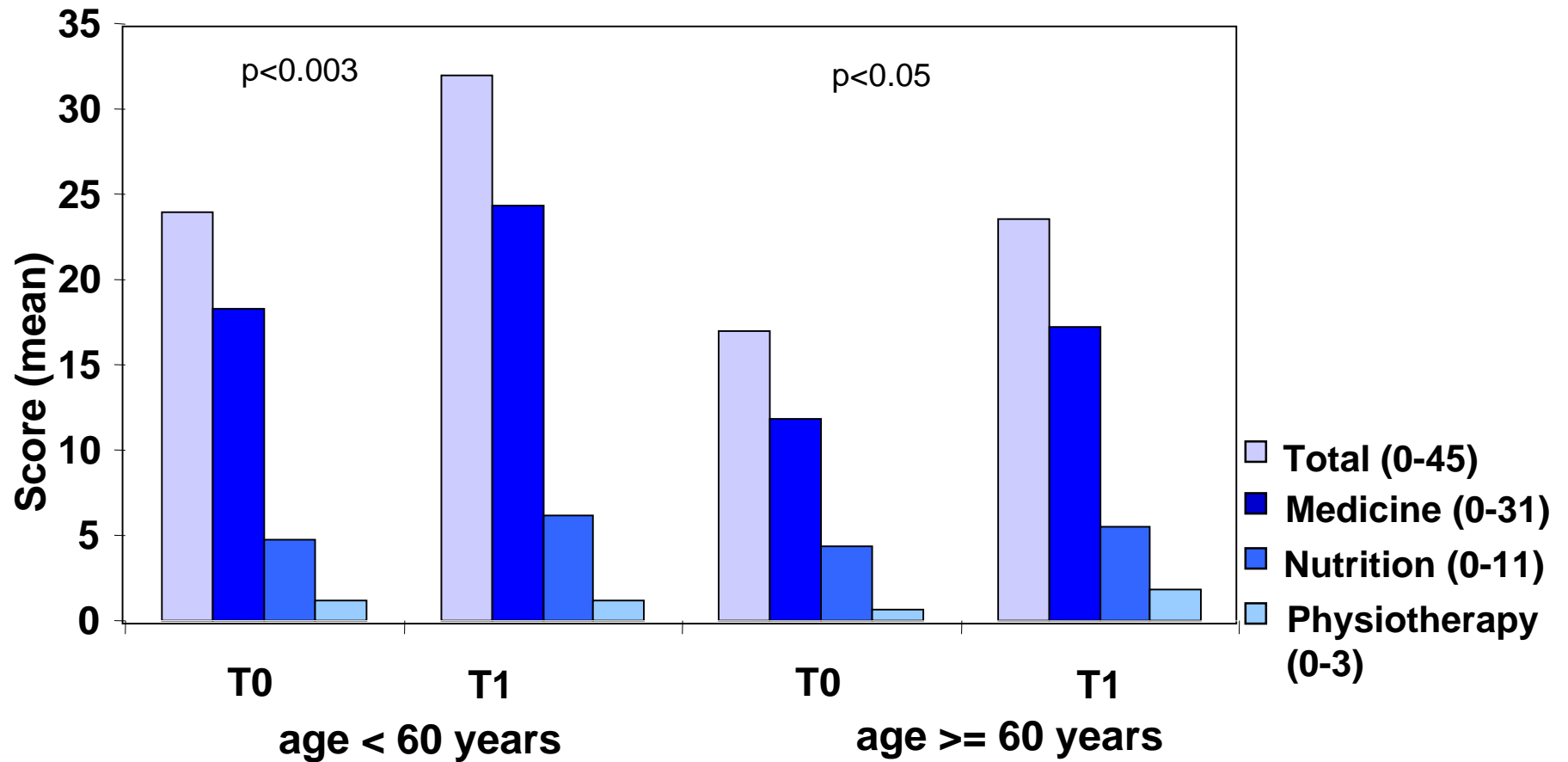
- 120 patients in 12 groups (09/2001 – 11/2006)
- 70 % female, 30 % male
- age (mean, range): 55.0 years (23-87)
- Vasculitides (%):

WG	24
Small vessel vasc.	7
CSS	14
MPA	6
Leukocytocl. vasc.	9
GCA	9
unclassified	11
- DEI (mean, range) 5.0 (0-9)
- Capability (mean, range) 5.3 (0-10)

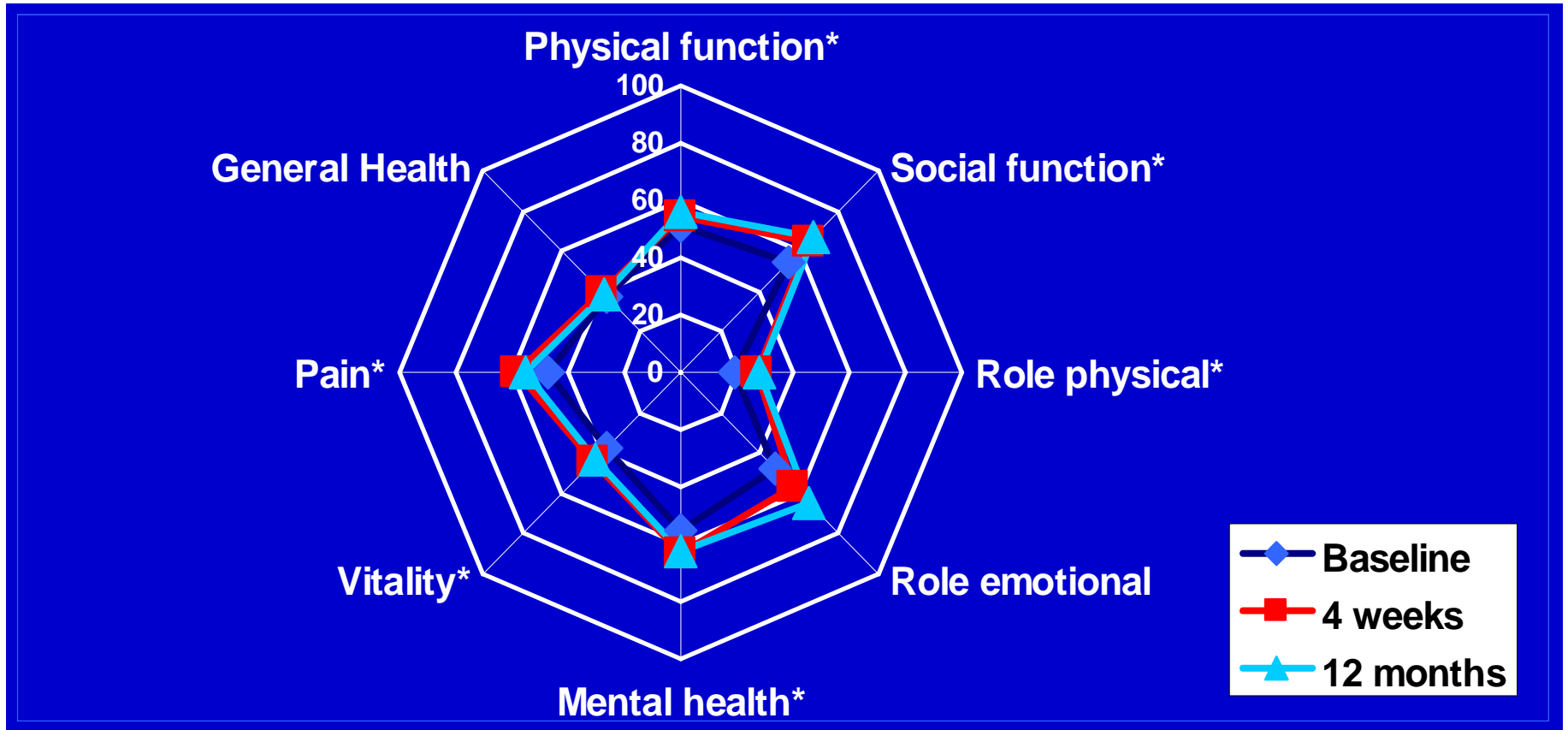
Results: Knowledge I



Results: Knowledge III



Results: Health-related quality of life (SF-36)



Summary

- **Statistically significant improvement of knowledge in all aspects**
- **Knowledge remains stable over 12 and 24 months**
- **Sign. increase of HRQL**
- **Sign. association with age**
- **No sign. association with disease duration**
- **No gender-related differences**

The vasculitis education program

- **has a positive and stable effect on patient knowledge**
- **seems to increase self-efficacy**
- **high acceptance and positive patient feedback**
- **useful additional treatment**

Future

- **Translation – Update – Evaluation**
- **Control group/new project**
- **Are relapses and side effects observed and treated earlier in the trained group?**

Thank you



Epidemiology group



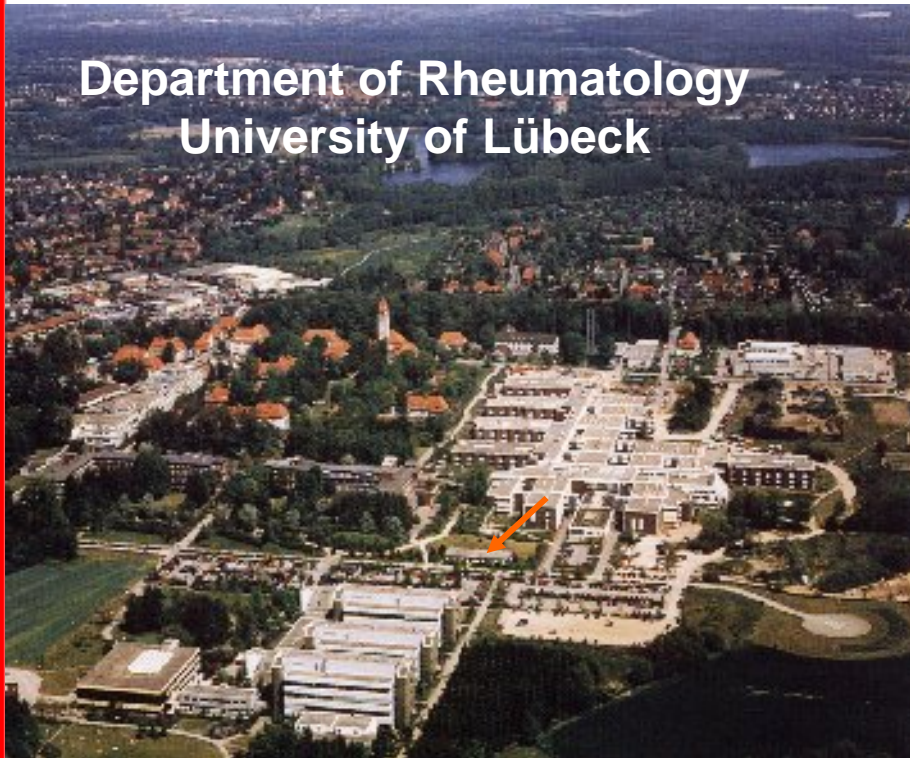
German support group

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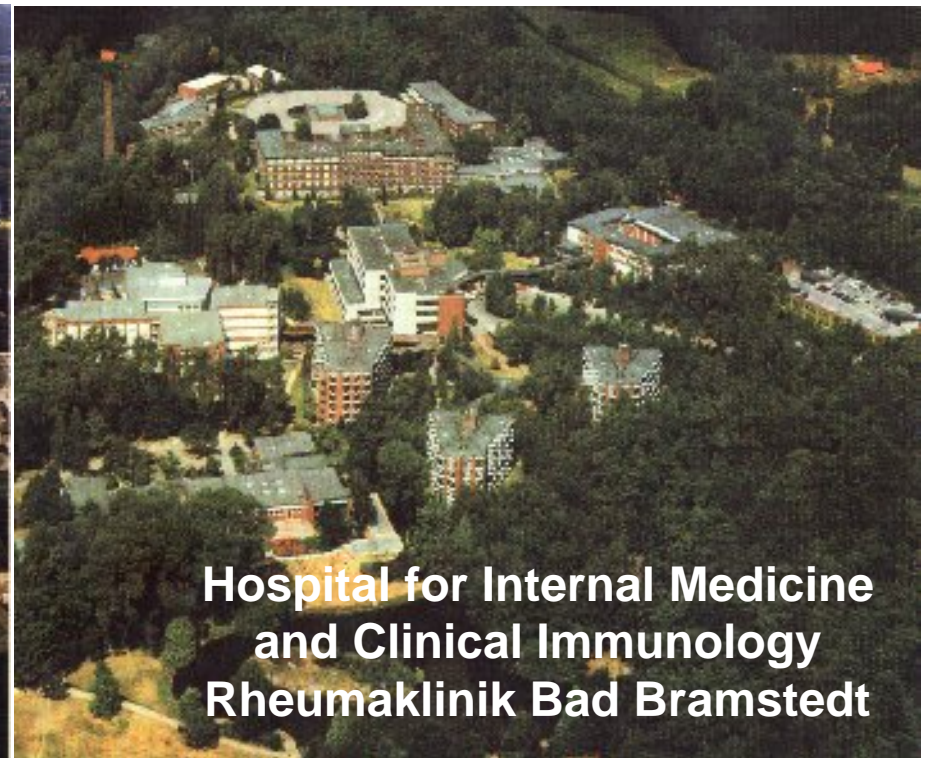
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