

# Focus on Health Services Research in Palliative Care - Study Designs, Instruments, Methods -

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Networking and Methods in Research on Palliative Care, BMBF Berlin, Kapelle-Ufer, 12.09.2017



**DIE DEUTSCHEN  
UNIVERSITÄTSKLINIKA®**

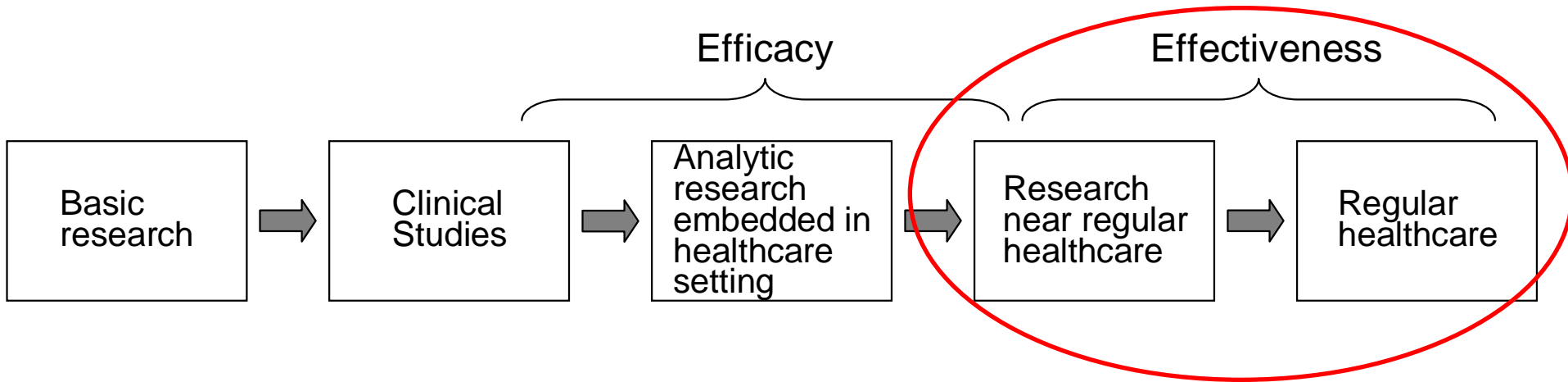
Wir sind Spitzenmedizin



# Health Services Research



Health Services Research is the scientific investigation of healthcare, both on the patient-individual and the population level with health-relevant products and services under everyday conditions (Arbeitskreis Versorgungsforschung beim wissenschaftlichen Beirat der Bundesärztekammer 2004)



# Research questions

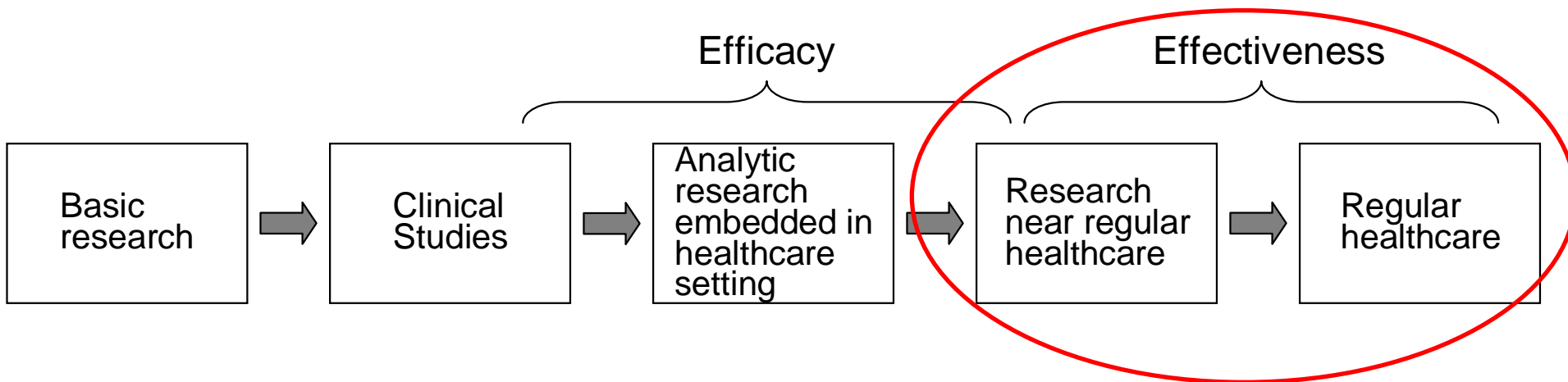


- Description of the healthcare situation
- Analysis of utilization of care
- Evaluation of the effectiveness of diagnostic / therapeutic methods, complex care pathways
- Development, implementation, evaluation of innovative healthcare concepts
- Evaluation of screening and early detection examinations
- Quality assurance (eg. adherence to guidelines, volume-effects on quality, patient safety, acceptance ...)
- Health economic cost analysis, cost-efficiency analysis, ...

# Health Services Research ...

... is the scientific investigation of healthcare, both on the patient-individual and on the population level with respect to health-relevant products and services under everyday conditions ...

(AK Versorgungsforschung beim wissenschaftlichen Beirat der Bundesärztekammer 2004)



**What is the difference to clinical trials?**

# Clinical trials vs Health Services Research



Clinical trials	Studies in Health Services Research
„Strict“ outcomes (eg. mortality, hospital admission, adverse events, ..)	Additional: Patient Reported Outcomes (quality of life, routine activities, mobility, ..), health-economic outcomes
Randomized Controlled Trials (RCTs)	<ul style="list-style-type: none"><li>– Pragmatic RCTs</li><li>– Cluster randomization</li><li>– Matching of patients or organizations</li><li>– Regional Comparisons</li><li>– Retrospective analyses with secondary data, control groups on the basis of matching</li><li>– Uncontrolled designs (well, really ??)</li></ul>
Single intervention (eg. medication, medical device)	Complex multidimensional interventions, comprising several / many components
Standardized intervention, fitting for all participants	Tailored, individualized interventions
Strict inclusion and exclusion criteria	Pragmatic inclusion and exclusion criteria

# Consequences for studies in Health Services Research



- Statistically noisy, often small effects
- Results less powerful, due to bias, methodological limitations
- Effects can be influenced by changes in the health system
- However: high external validity, relevant for real-life-care

**Do we need Health Services Research in palliative care?**

# Liverpool Care Pathway I



*Liverpool Care Pathway for the Dying Patient (LCP):*

UK care pathway (excluding Wales) covering palliative care options for patients in the final days or hours of life. Developed in the late 1990s to help doctors and nurses provide high quality end-of-life care.

1. Patient identification
2. Assessment to identify the special needs of the patient
3. Suggestions for specific palliative care options
4. Suggestions which non-essential treatments and medications should be discontinued

Initial assessments of the effects of the pathway were largely positive:

- High acceptance among nurses and physicians
- Decrease in the use of medication that might shorten life
- Increased patients' involvement in their medication and care
- Enhancing patient dignity, symptom management and communication with families

Quellen:

- Jack BAM et al. 2003. *Int J Palliat Nurs.* 9 (9): 375–81.  
van der Heide A.L et al. 2009. *J Pain Symptom Manage.* 39 (1): 33–43.  
Mullick, A., T. et al. 2009. *Palliat Med.* 23 (6): 571–2.

# Liverpool Care Pathway II



2009: launching of Version 12 of the LCP

Among other revisions, version 12 included:

- new decision-making support on whether or not to start the LCP
- highlighted guidance to review the appropriateness of continuing on the pathway at any time if concern is expressed by either the patient, a relative, or a team member
- new prompts to support decisions on artificial nutrition and hydration

Then, the opinion changed ...

**Eg. Daily Telegraph, 2009:**

**„ ... hastening the death of some mortally ill patients ...”**



# Liverpool Care Pathway III



2013: Independent review of LCP. Results:

- poor implementation and practice
- lack of thought
- poor training
- inadequate communication

## KEY POINTS

Recommendation: the use of the LCP should be "phased out over the next 6-12 months and be replaced with an individual approach to end of life care for each patient".

## And lack of health services research during and after implementation ?

the way they care for older people, and show more empathy.

- The willingness of so many health-care bodies to come together to look at a way forward is a positive sign.
- High quality clinical leadership, training and enthusiasm for 'getting it right' is key to improving care for dying patients.

# Health Services Research in palliative care is difficult



- Ethical considerations (can these patients be "bothered" with research?)
- Design - adaptations due to low life expectancy of many patients
- Research setting – usually the homes of the patients
- Standardized assessment
- Sample size calculation
- Identification and recruitment of patients
- Follow-up examinations (dealing with drop outs, ...)
- Involvement of family members
- ...

# But: Many themes, challenges, goals, outcomes, ....



- Diagnostics, therapy, monitoring in different settings
- Access to palliative care
- Pts. with different cultural backgrounds
- Pts. reported outcomes (eg quality of life, coping, preference,...)
- Transitions between sectors in the healthcare system
  - Hospital – ambulant care – hospice – nursing home ...
  - Cooperation of physicians, nurses, other professions
  - ..
- Advanced care planning
- Palliative care in rural regions (integration with regional care, reasonable distribution of tasks, telemedicine, ...)
- Conflict management in the care team
- ...

# It affects many patient groups



- Cancer
- Neurological diseases (e.g. amyotrophic lateral sclerosis, multiple sclerosis)
- Pts. with geriatric symptom complex
- Chronic heart, pulmonary and/or kidney diseases
- HIV / AIDS
- All ages: Children, adults, old people
- ...

# (Very) heterogenous settings



## **Inpatient palliative care:**

- (Rural) hospital
- Palliative care wards
- Other palliative care services at the hospital
- (Hospice)

## **Outpatient palliative care:**

- General practitioners
- Physicians with subspecialty palliative care
- AAPV (general)
- SAPV (specialized)



## **Different settings → different data sources**

**Primary data, actively assessed within research projects**

**Reimbursement („Secondary“) data**

**Hospital data**

DRG (Diagnose related groups) , OPS (Operations- und Prozedures)

Sources:

- Statutory Health Insurances
- DIMDI (German Institute of Medical Documentation and Information)
- INeK
- German Statistical Office (highly aggregated data)
- Hospital quality reports
- ...



# Different settings → different data sources

## **Outpatient reimbursement data:**

EBM (Einheitlicher Bewertungsmaßstab )

GOP (Gebührenordnungsposition)

### Sources:

- Statutory Health Insurances
- Federal Association of SHI Physicians (Kassenärztliche Bundesvereinigung)
- ...

### **Other:**

- German Hospice and Palliative Association
- HOPE (Institution: German Palliative Care Society)
- Guide Hospice and palliative care (Wegweiser Hospiz und Palliativmedizin)
- ...

# Chairs of Health Services Research 2017



## Academic Structures for health services research in Palliative care ?





# Chairs of Health Services Research and Palliative Care 2017



**Academic Structures for health services research in Palliative care ?**

# Akademische Strukturen für Versorgungsforschung in der Palliativmedizin ?



## Sprecher der AG



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Tel. 0221 478-3361  
Fax 0221 478-89300

zu sein. Einerseits kann so die Pallia  
ver mit Themen der Palliativversorgu

lick auf die Notwendigkeit der Übera

09.10.2015 in der Urania in Berlin un



# Memorandum III: Methoden für die Versorgungsforschung (Teil I)

Memorandum des Deutschen Netzwerks Versorgungsforschung

Autoren  
Institute

## Memorandum III: Methoden für die Versorgungsforschung (Teil 2)\*

Memorandum des Deutschen Netzwerks Versorgungsforschung

Autoren  
Institute

## Epidemiologische Methoden für die Versorgungsforschung\*

Memorandum des Deutschen Netzwerks Versorgungsforschung

Autoren  
Institute

## Die Erfassung von Lebensqualität\* in der Versorgungsforschung – konzeptuelle, methodische und strukturelle Voraussetzungen\*\*

Memorandum des Deutschen Netzwerks Versorgungsforschung

Autoren  
Institute

## Methoden für die organisationsbezogene Versorgungsforschung\*

Methods for Organisational Health Services Research

# 2014: Joint 13th Kongress für Versorgungsforschung with 10th Kongress Deutsche Gesellschaft für Palliativmedizin



**Deutsches Netzwerk  
Versorgungsforschung e.V.**

# DNVF

[Kontakt](#)  
[Impressum](#)

## Aktuelle News

[Das DNVF](#)

[Arbeits-/Fachgruppen](#)

[Mitglied werden](#)

## DKVF

[DKVF 2017](#)

[DKVF 2016](#)

[DKVF 2015](#)

[DKVF 2014](#)

[DKVF 2013](#)

[DKVF 2012](#)

[DKVF 2002-2011](#)

## Veranstaltungen

[DNVF-Spring-School](#)

[Pre-Conference-Seminare](#)

[Wilfried-Lorenz-VF-Preis](#)

[Stellungnahmen](#)

[Memoranden](#)

[Publikationen](#)

[Veranstaltungskalender](#)

## **DKVF 2014**

Der **13. Kongress für Versorgungsforschung (DKVF)** fand vom **24.-27.06.2014** zusammen mit dem **10. Kongress der Deutschen Gesellschaft für Palliativmedizin** im CCD - Congress Center Düsseldorf statt. Ausrichter war die Deutsche Gesellschaft für Palliativmedizin.

[>> Kongresswebseite](#)

Eine Auswahl an Vorträgen haben wir für Sie um Download bereitgestellt:

Hecken: Innovationsfonds, Versorgungsforschung und der Gemeinsame Bundesausschuss [>>](#)

Schrappe: P4P und Versorgungsforschung - Ansätze zur effektiven Unterstützung politischer Entscheidungsprozesse [>>](#)

## **Posterpreisträger**

Im Rahmen des DKVF wurden insgesamt 4 Posterpreise verliehen. In den Kategorien aus dem Bereich der Versorgungsforschung wurden folgende 2 Poster prämiert.

**Der Posterpreis der Kategorie „Palliativmedizin und Versorgungsforschung“ (PC) ging an die Forscher:**

Becker C. (1), Laryionava K. (2), Christ C. (1), Hiddemann W. (1), Winkler E.C. (2), Heussner P. (1) für den Beitrag: **Empirische Untersuchung der Entscheidungspraxis zur Therapiebegrenzung (TBE) am Lebensende in der universitären Hämatologie-Onkologie**

(1) Klinikum der Universität München. Medizinische Klinik und Poliklinik III - Großhadern, München, Deutschland und (2) Nationales Centrum für Tumorerkrankungen (NCT), Heidelberg, Deutschland

**Poster** [>>](#)

# 4. - 6.10.2017, Urania, Berlin



## Kongressformate

- Pre-Conference-Seminar
- Plenarvortrag
- Vortragssession
- Geführte Postersession
- Science Slam
- Forum Pro Contra
- Podiumsdiskussion
- Frühstückssession/Meet the Expert

## Mecklenburg-Vorpommern als starker Partner



Das Land Mecklenburg-Vorpommern (M-V) übernimmt die Länderpartnerschaft des 16. DKVF. M-V gilt als Modellregion für die Auswirkungen des demographischen Wandels auf die Alterszusammensetzung der Bevölkerung und die Veränderungen der Morbidität.

In seiner Keynote wird Harry Glawe, Minister für Wirtschaft, Arbeit und Gesundheit, am Beispiel M-V aktuelle Herausforderungen für die Versorgung insbesondere der ländlichen Gebiete vorstellen und Bedarfe für die Entwicklung, Implementierung und Evaluation innovativer Versorgungskonzepte benennen. In einer Landes-Session werden ausgewählte Projekte aus der Region M-V und Lösungen, die dort entwickelt werden, vorgestellt.

## Transparenzvorgabe

Der Kongress ist u.a. industriefinanziert. Wir informieren ab Juni 2017 unter [www.dkvf2017.de](http://www.dkvf2017.de) über die finanzielle Unterstützung der Industrie gemäß deren Mitgliedschaft im FSA e.V., im AKG e.V. oder weil die Unternehmen die Veröffentlichung genehmigt haben.

## Allgemeine Informationen

### Tagungsort

Urania Berlin e.V.  
An der Urania 17 | 10787 Berlin  
N52° 30' 5.594" E13° 20' 53.437"  
[www.urania.de](http://www.urania.de)

### Datum

4. - 6. Oktober 2017

### Deadline Abstracteinreichung

31. März 2017

### Kongresshomepage

[www.dkvf2017.de](http://www.dkvf2017.de)

### Wissenschaftliche Leitung

Deutsches Netzwerk Versorgungsforschung e.V.  
Eupener Straße 129 | 50933 Köln  
Tel. + 49(0)221 47897115  
[dnvf@uk-koeln.de](mailto:dnvf@uk-koeln.de)  
[www.dnvf.de](http://www.dnvf.de)

### Kongresspräsident

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### Kongressagentur

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## Deutscher Kongress für Versorgungsforschung

16. Kongress | 4. - 6.10.2017 | Urania - Berlin

### Zukunft Regionale Versorgung – Forschung, Innovation, Kooperation



## Save the Date

Deutsches Netzwerk  
Versorgungsforschung e.V.

[www.dkvf2017.de](http://www.dkvf2017.de)





# Case Study

The implementation of telemedical functionalities  
in outpatient palliative care  
- Pilot study -

# Background



64- 84% of palliative patients prefer to die at home<sup>1</sup>

25- 30% of palliative patients die at home, receiving regular care<sup>2</sup>

Patients die in the:

- hospital (43%)
- nursing home (25%)
- Hospice (2%)<sup>2</sup>

With additional care (eg. 24h- emergency services), up to 78% of the palliative patients can die at their homes<sup>3</sup>

Aus dem Institut für Community Medicine  
Abteilung Versorgungsepidemiologie und Community Health  
(Direktor: Univ.- Prof. Dr. med. W. Hoffmann, MPH)  
der Universitätsmedizin der Ernst-Moritz-Arndt-Universität Greifswald

**Telemedizinische Betreuung von Palliativpatienten-  
Eine Pilotstudie zur Machbarkeit und zu Auswirkungen auf patientenbezogene  
Parameter**

Inaugural - Dissertation  
zur  
Erlangung des akademischen  
Grades  
Doktor der Medizin  
(Dr. med.)  
der  
Universitätsmedizin  
der  
Ernst-Moritz-Arndt-Universität  
Greifswald  
2013

vorgelegt von: Tatjana Mues  
geb. am: 19.02.1988  
in: Soest

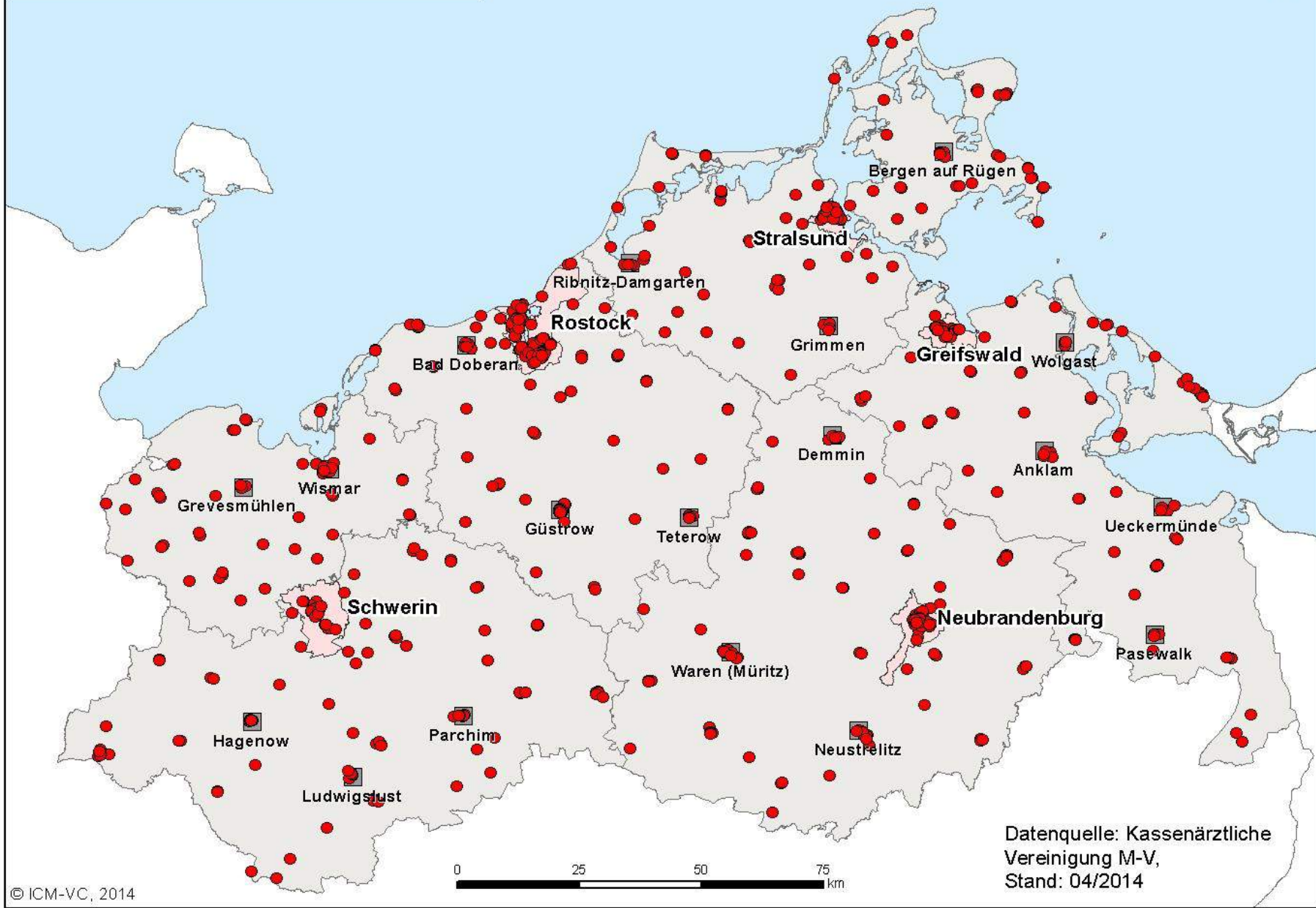
1 Gomes et al., 2012

2 Jaspers B et al., 2005

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● vertragsärztlich tätige Allgemeinmediziner

☒ Oberzentren

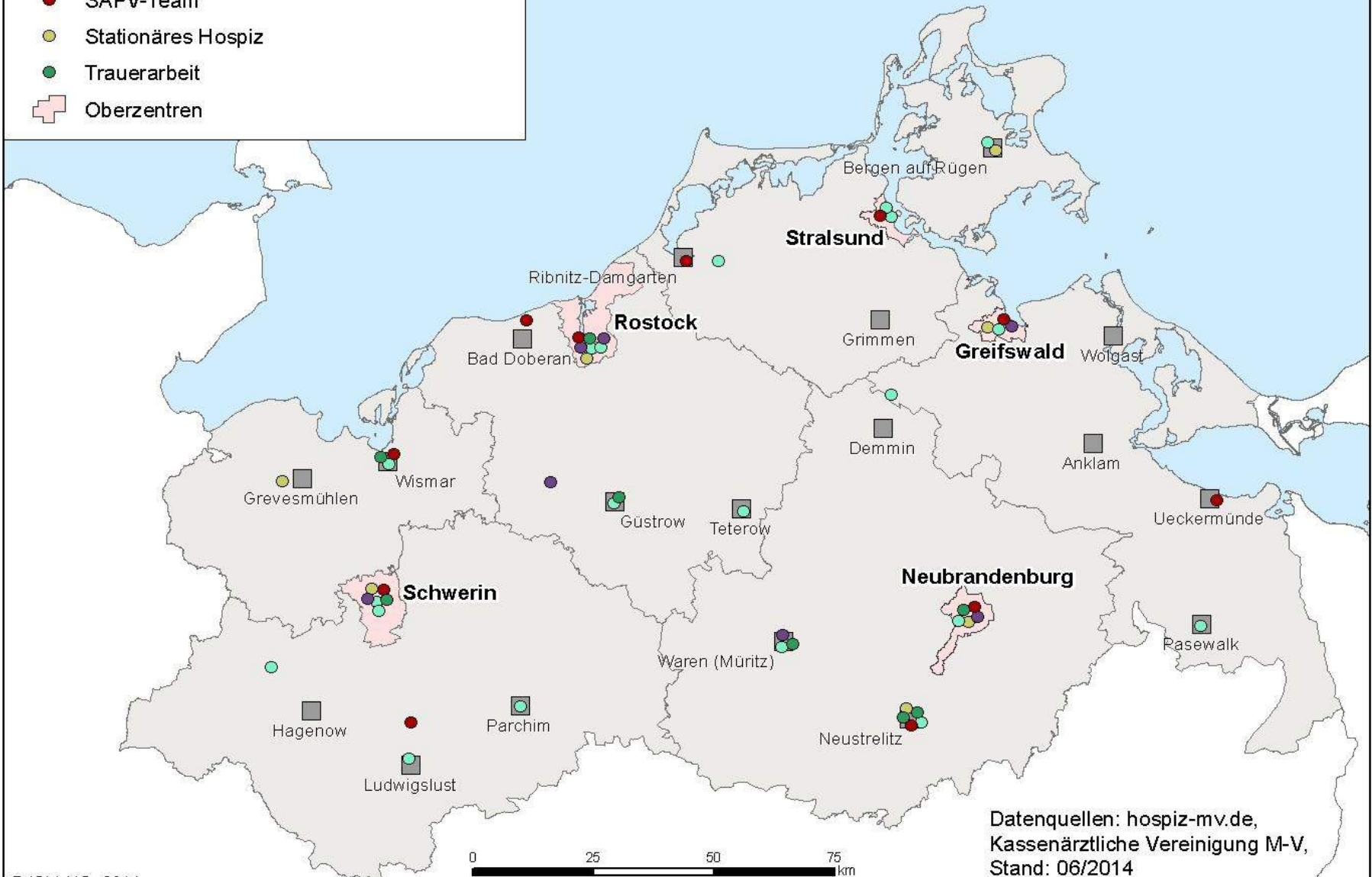


Datenquelle: Kassenärztliche  
Vereinigung M-V,  
Stand: 04/2014



# Einrichtungen der Palliativversorgung

-  Ambulanter Hospizdienst
-  Palliativstation
-  SAPV-Team
-  Stationäres Hospiz
-  Trauerarbeit
-  Oberzentren



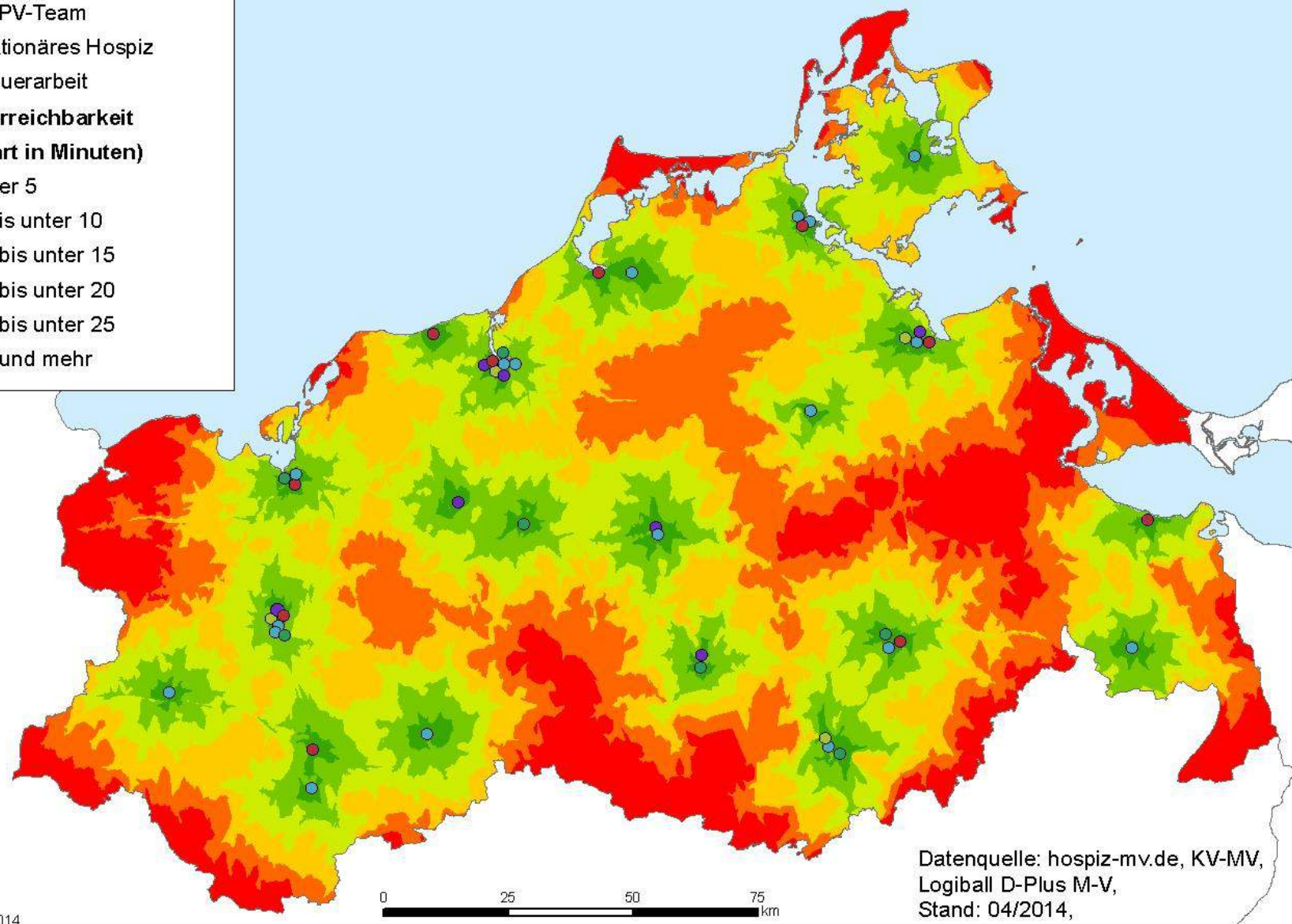
Datenquellen: hospiz-mv.de,  
Kassenärztliche Vereinigung M-V,  
Stand: 06/2014

## Palliativversorgung,

- Ambulanter Hospizdienst
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- Trauerarbeit

## PKW-Erreichbarkeit (Hinfahrt in Minuten)

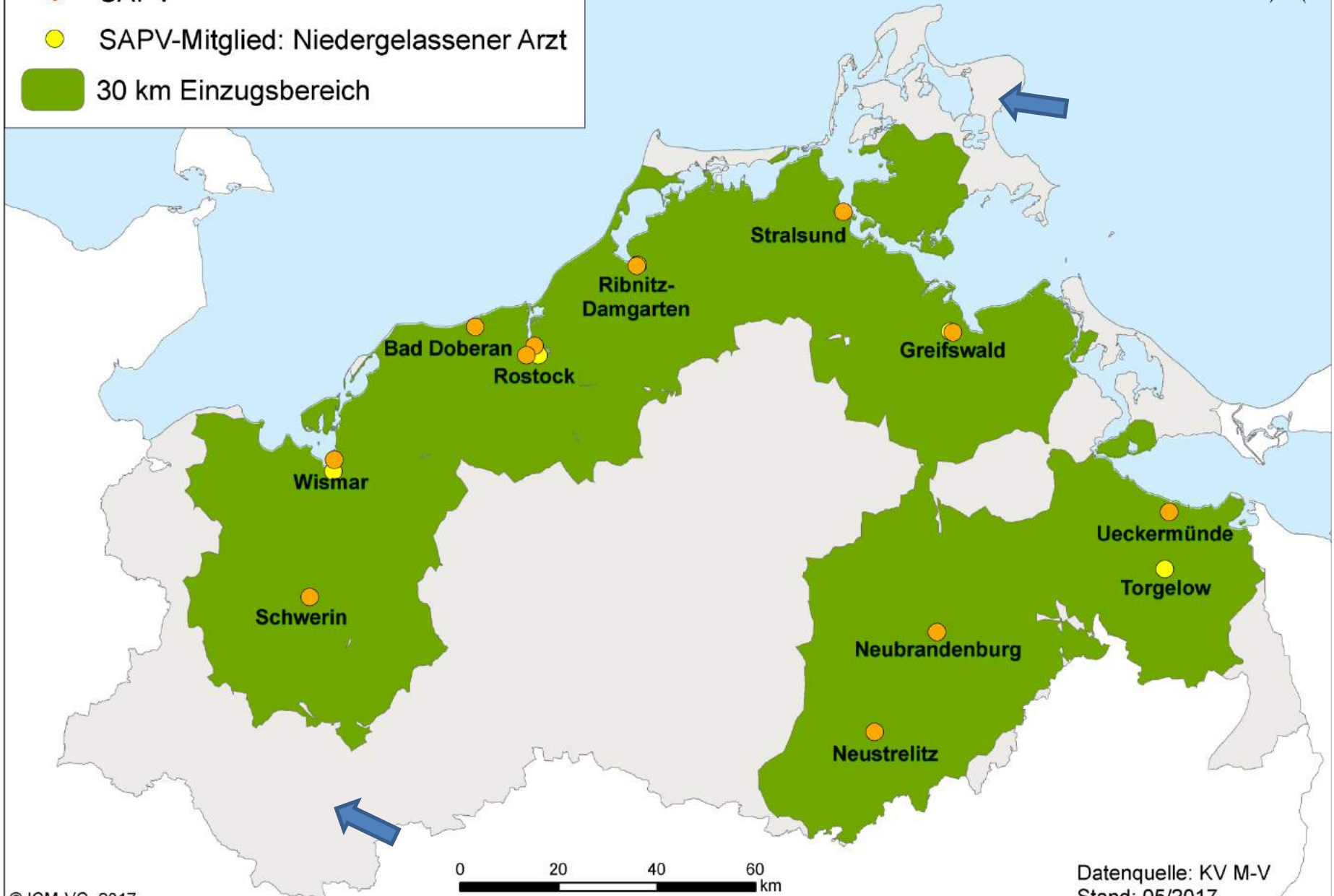
- unter 5
- 5 bis unter 10
- 10 bis unter 15
- 15 bis unter 20
- 20 bis unter 25
- 25 und mehr



Datenquelle: hospiz-mv.de, KV-MV,  
Logiball D-Plus M-V,  
Stand: 04/2014,

# Standorte 2017

- SAPV
- SAPV-Mitglied: Niedergelassener Arzt
- 30 km Einzugsbereich



# Telemedicine in outpatient palliative care



## Research questions:

- Can regular telephone calls by qualified nurses support adequate outpatient palliative care?
- Is it possible to perform a randomized design in this patient group?

## Qualification of the palliative care nurses:

- Examined nurses with working experience
- Basic qualification „Palliative Care“ (160h)
- Qualification to use the IT-supported documentation system

## Intervention:

Regular telephone calls by qualified nurses

Contents of telephone calls:

- Standardized: assessment of pain and complaints
- Individual: personal, medical, therapeutical, or organizational problems

# Design and methods of the study I



- **Randomized controlled design** (randomization on the patient level)
- **Inclusion criteria:**
  - No need for inpatient care at baseline
  - Outpatient care in the home of the patient is possible
  - Living in the region Western Pomerania
- **Primary outcome:** feasibility and acceptance
- **Secondary outcomes:**
  - Pain
  - Symptoms
  - Quality of life
  - Mobility, activity
  - Physician contacts
  - Hospital admissions

# Design and methods of the study II



**Recruitment:** pain clinic of the University Medicine Greifswald

**Baseline assessment:** Computer assisted telephone interviews

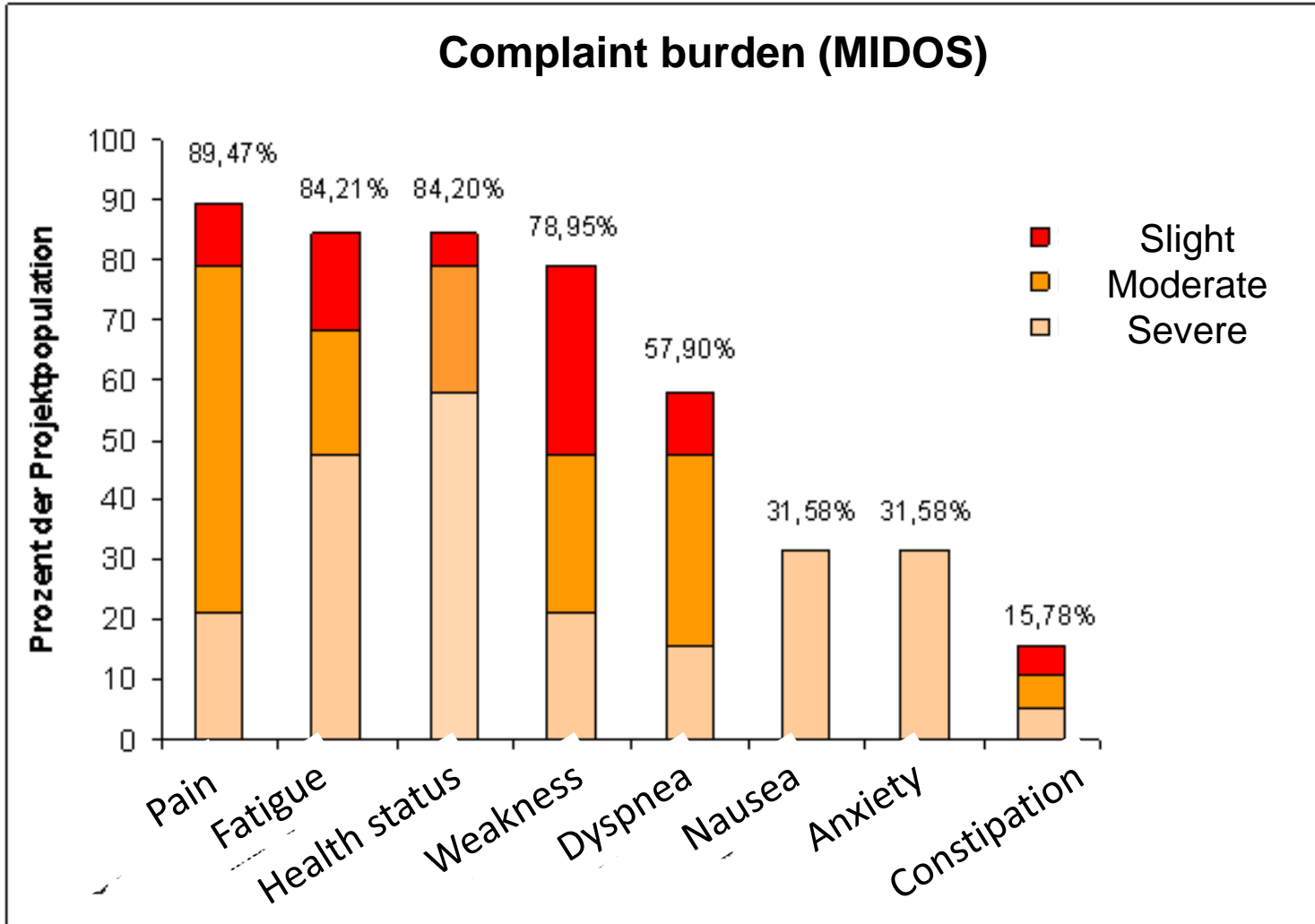
Standardized assessment:

- Minimal Documentation System (MIDOS: pain, complaints, need medication)
- Quality of Life (SF-12)
- Karnofsky index (performance status)
- Mobility
- Medication
- Physician contacts, hospital admissions

**Follow up** after three months, shorter time period if necessary



# Baseline analysis



Score of the complaint burden



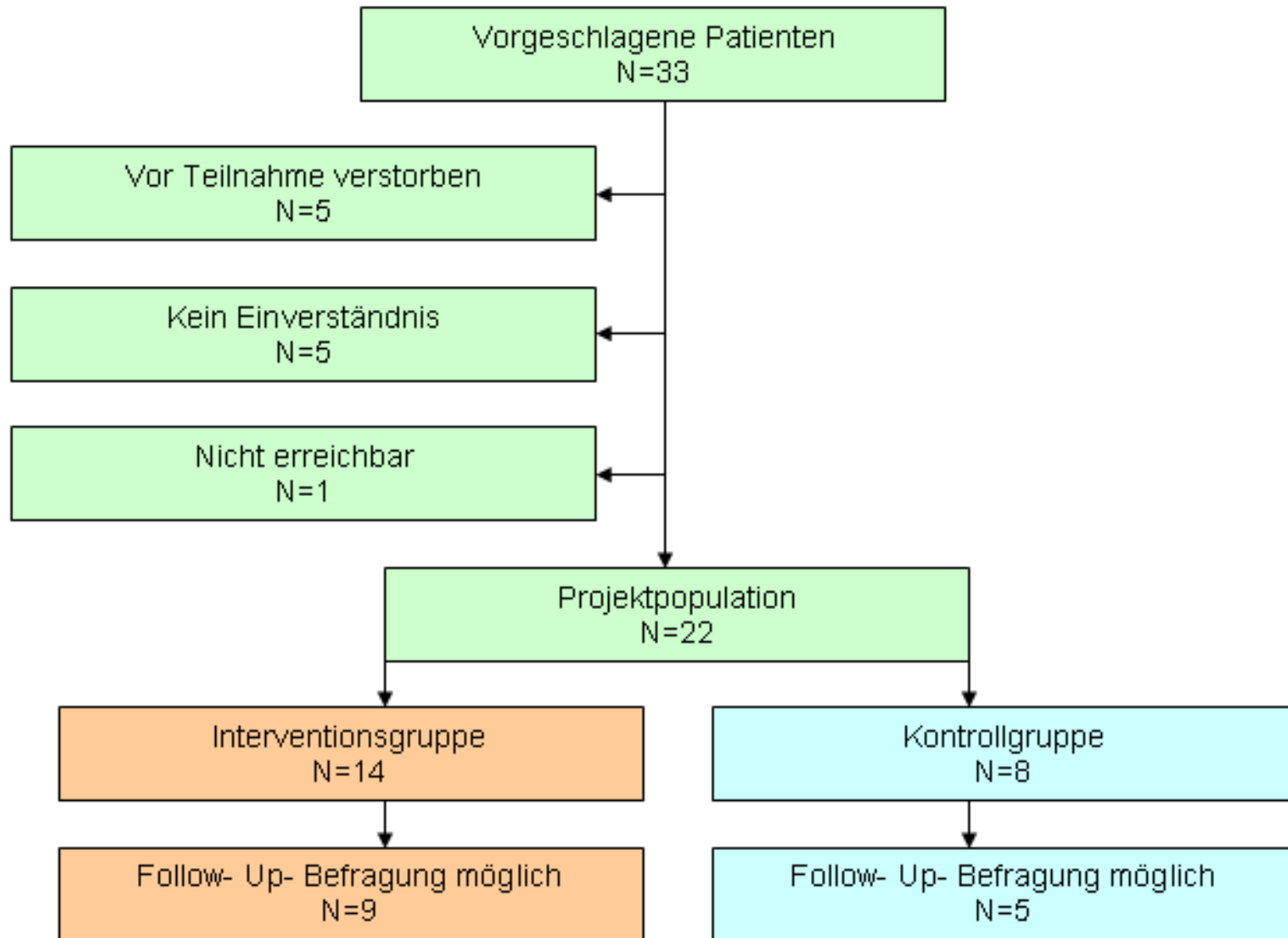


**TED:**

**Is it possible to perform a randomized design in this patient group ?**



# Flowchart of the project



# Patient characteristics



	Females	Males
IG	57% (N=8)	43% (N=6)
KG	50% (N=4)	50% (N=4)

## Age

	N	MW	Min.	Max
IG	14	62,79	49	77
KG	8	64,63	45	84

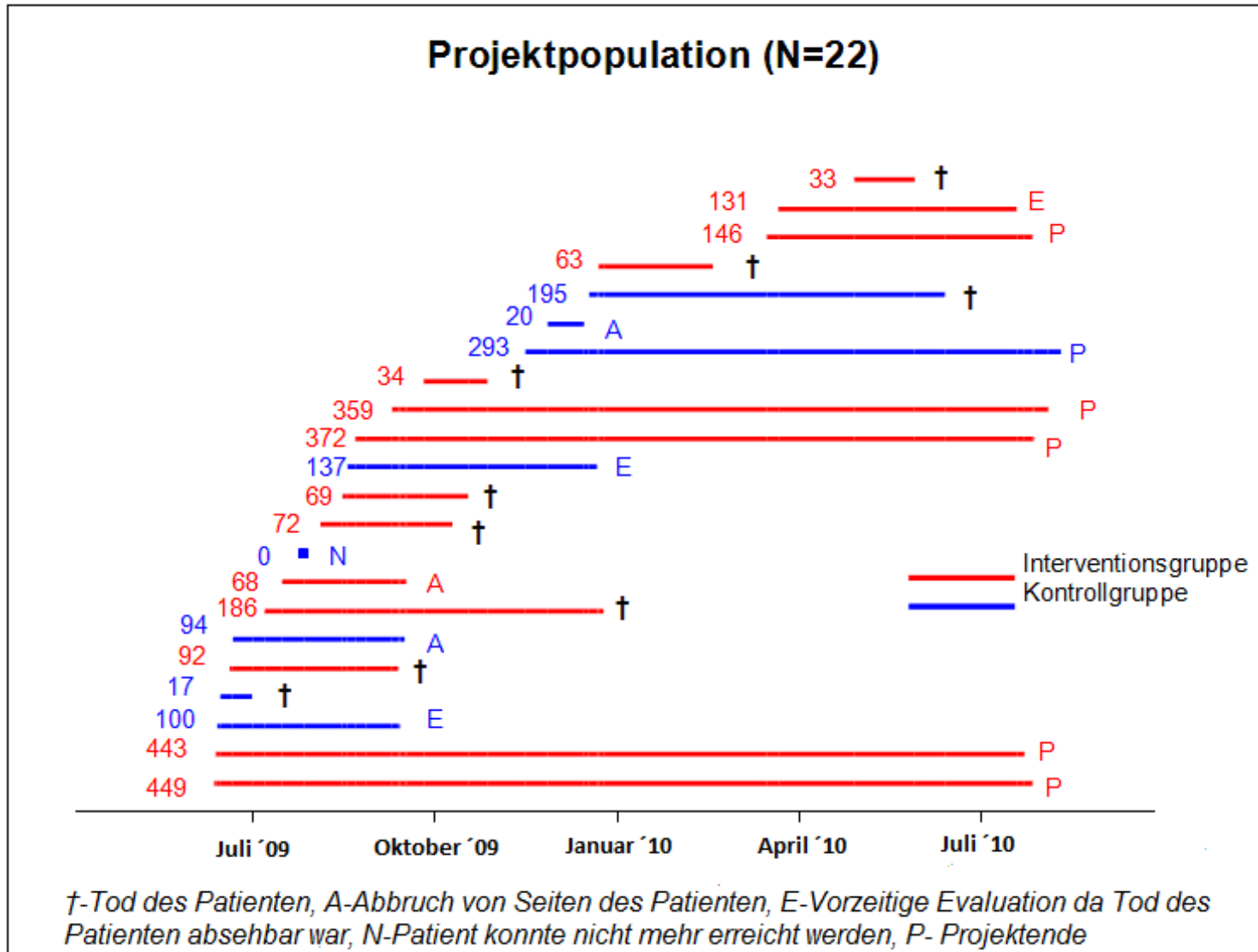
IG: Intervention group

KG: Control group

## Diagnoses

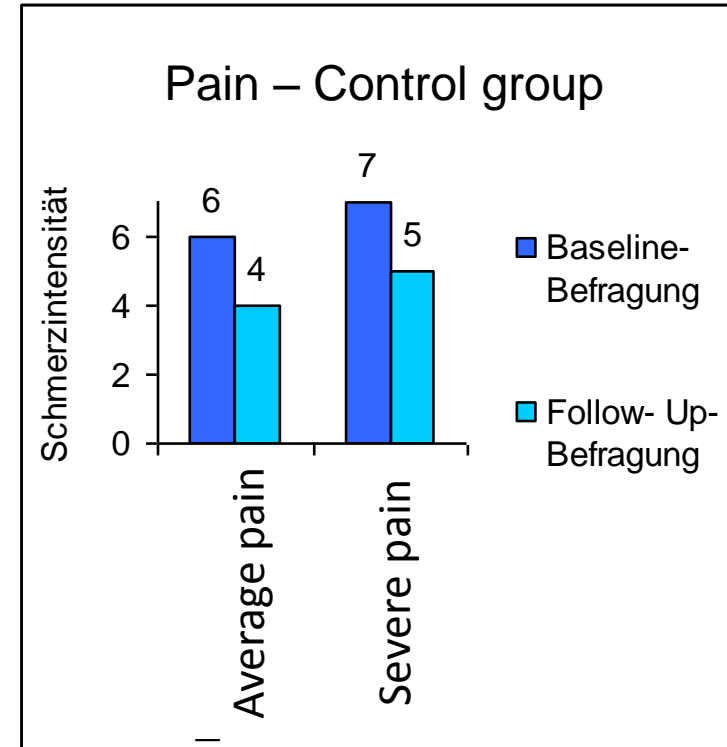
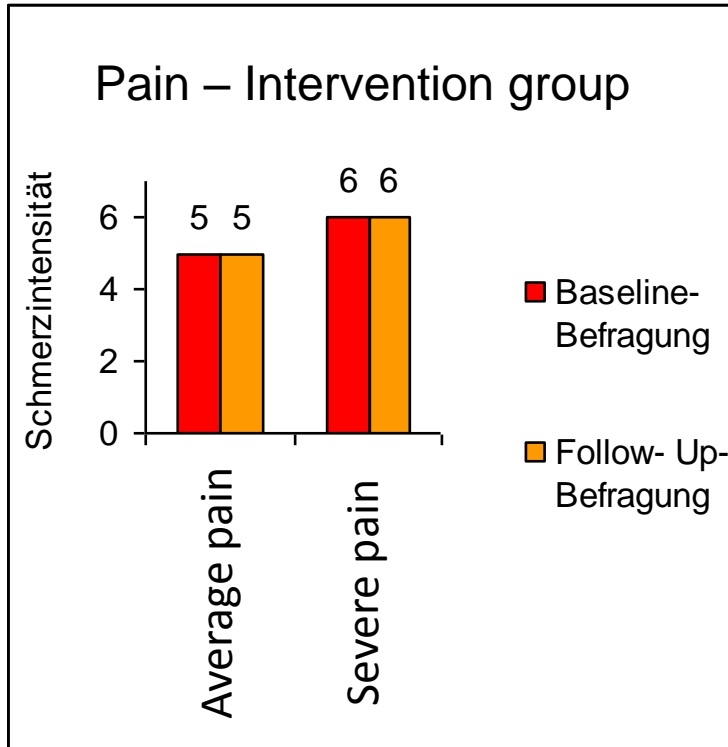
Tumors of lymph nodes and bone marrow	23% (N=5)
Breast cancer	18% (N=4)
Prostate Cancer	14% (N=3)
Colon cancer	14% (N=3)
Head and neck tumors	9% (N=2)
Gynecological tumors	9% (N=2)
kidney cancer	5% (N=1)
Other tumors	9% (N=2)

# Time period of the patients in the project



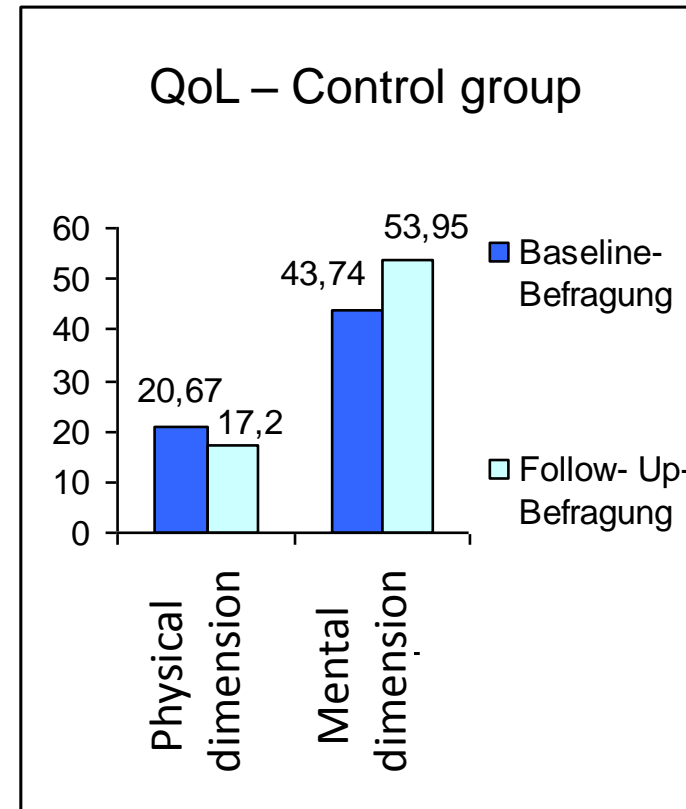
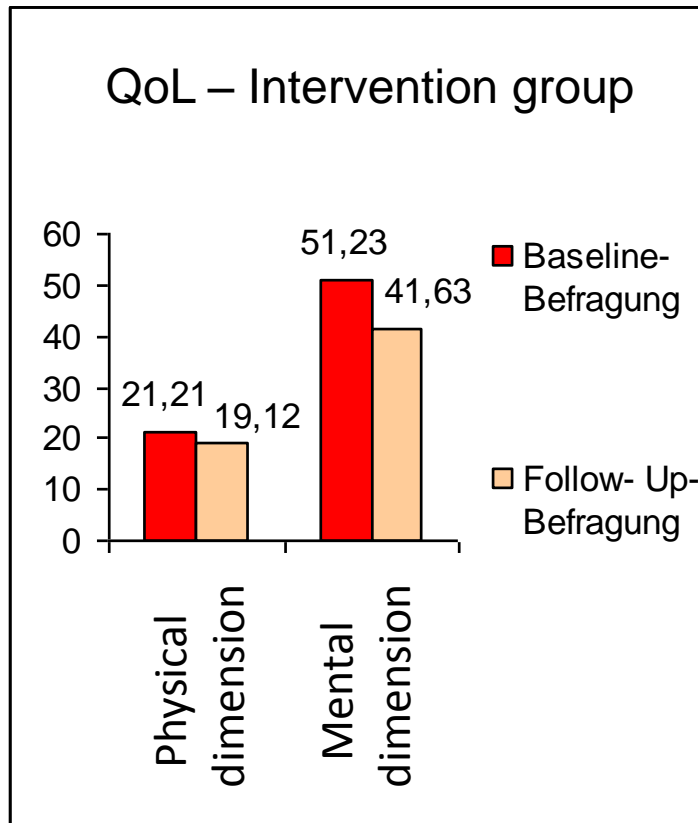
- 13,6 % (N=3) of the patients left the project
- (N=1): no strength/resources for further home visits

# Patient reported outcomes - pain



**No significant difference between the groups at follow-up**

# Patient reported outcomes – Quality of life



**No significant difference between the groups at follow-up**



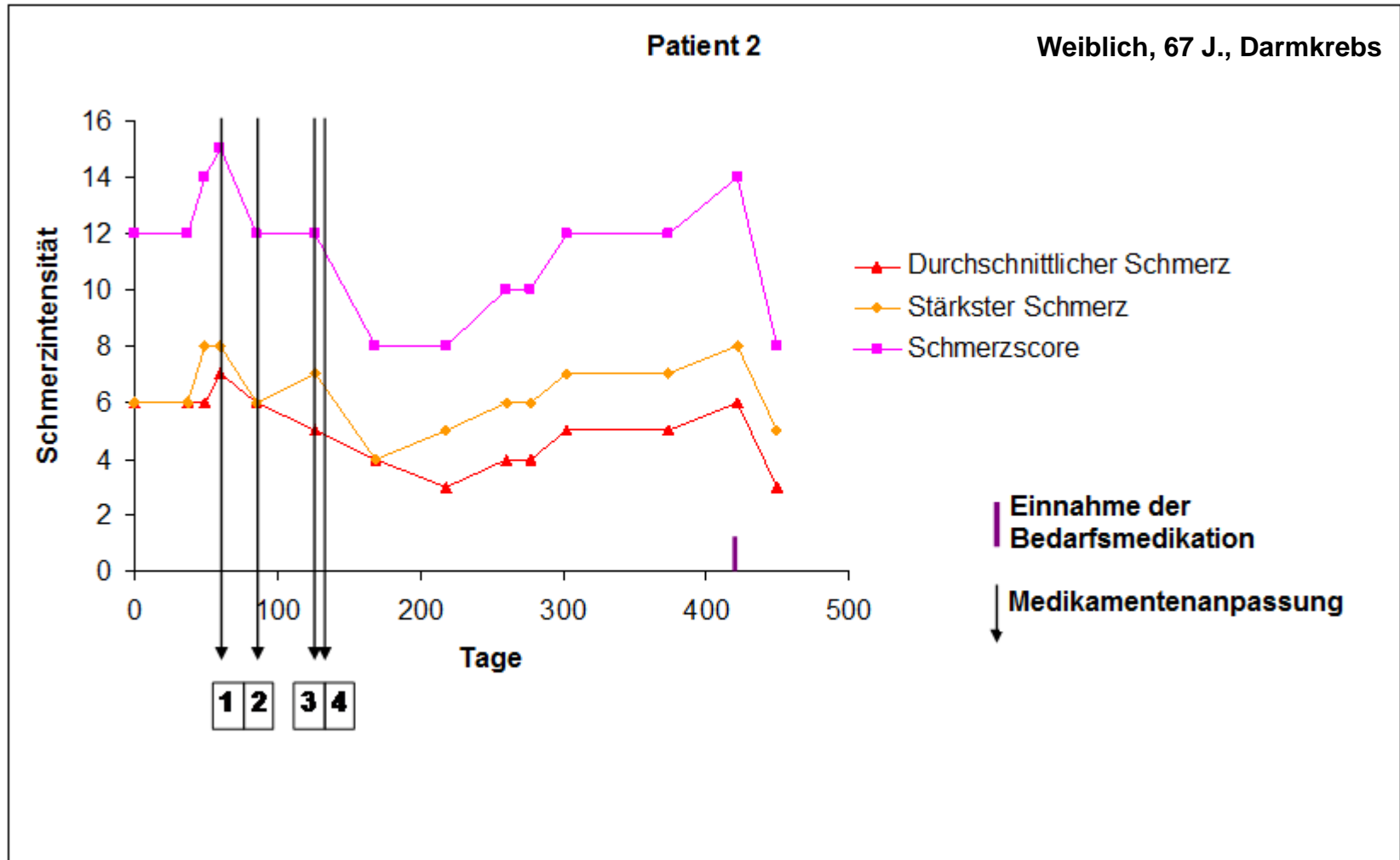
**TED:**

**Do we rather need a standardized intervention  
or a standardized outcome ?**

# Patient individual analysis



# Patient individual analysis







**TED:**

**Do palliative patients accept telemedicine as a part of their care ?**



## What is your opinion about the telemedical care concept?

• „very good“ N=4	↙ ↘	„Patient is sad, because the project finished.“
• „good“ N=2	→	„Patient was very satisfied, he would have liked to continue“
• „not so good“ N=1	→	„Patient and spouse were satisfied with the project.“
		„The project is pointless because it does not go any further.“

# Discussion and conclusion



Prospective intervention study in palliative care difficult:

- Some patients die before randomization
- Randomization: N intervention : control group = 2:1
- Follow-up challenging
- number of patients at follow-up is too small to compare the groups

Positive:

- Feasibility and acceptance → Regular telephone calls feasible and accepted, addition to routine palliative care
- High information density: patient-individual descriptions are possible
- Patient-individual care is possible – also in telemedicine concepts



**Thank you for your attention!**





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Titelbild Doktorarbeit Tatjana

With additional care (eg. 24h- emergency services) , up to 78% of the palliative patients can die at their homes<sup>3</sup>

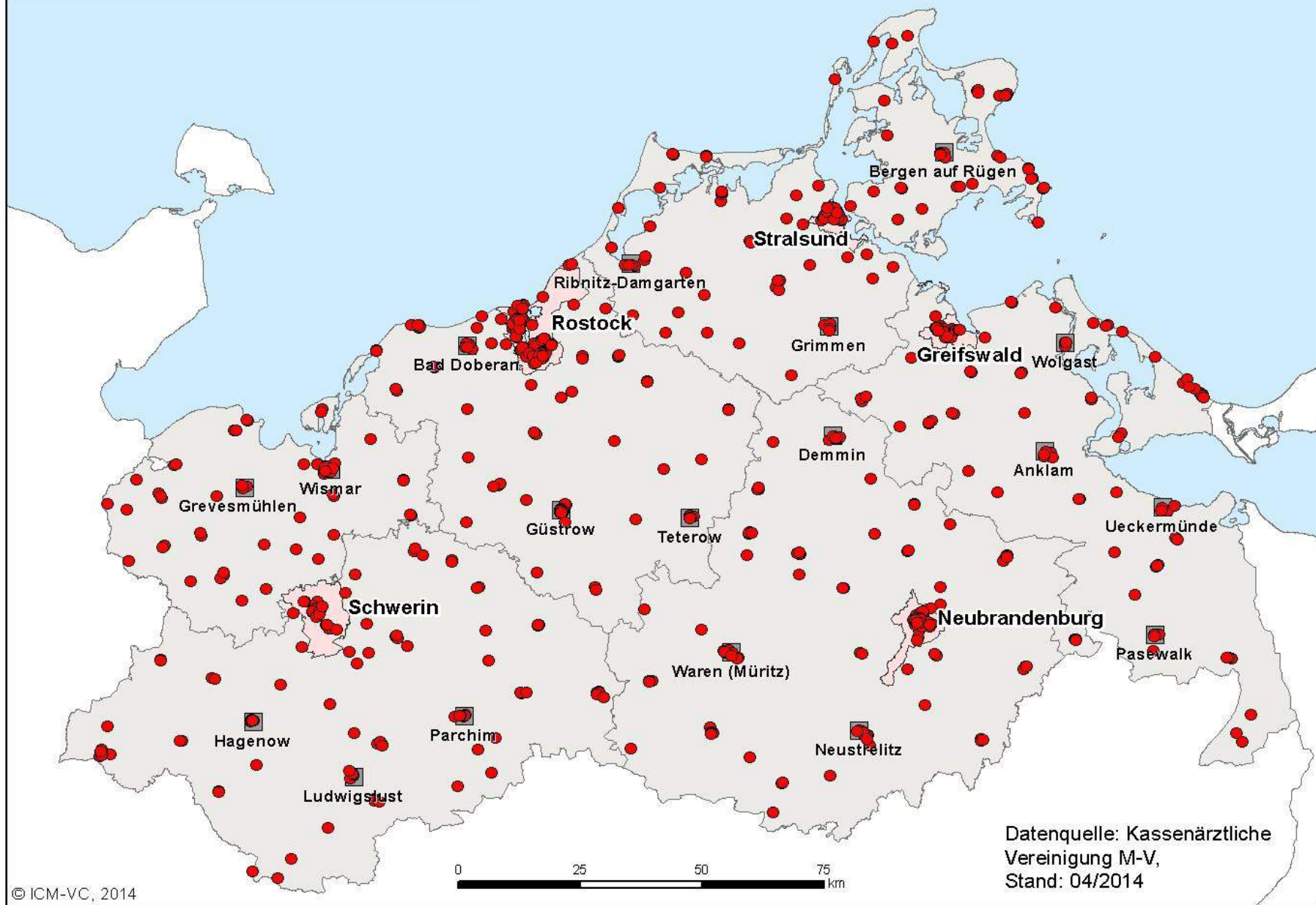
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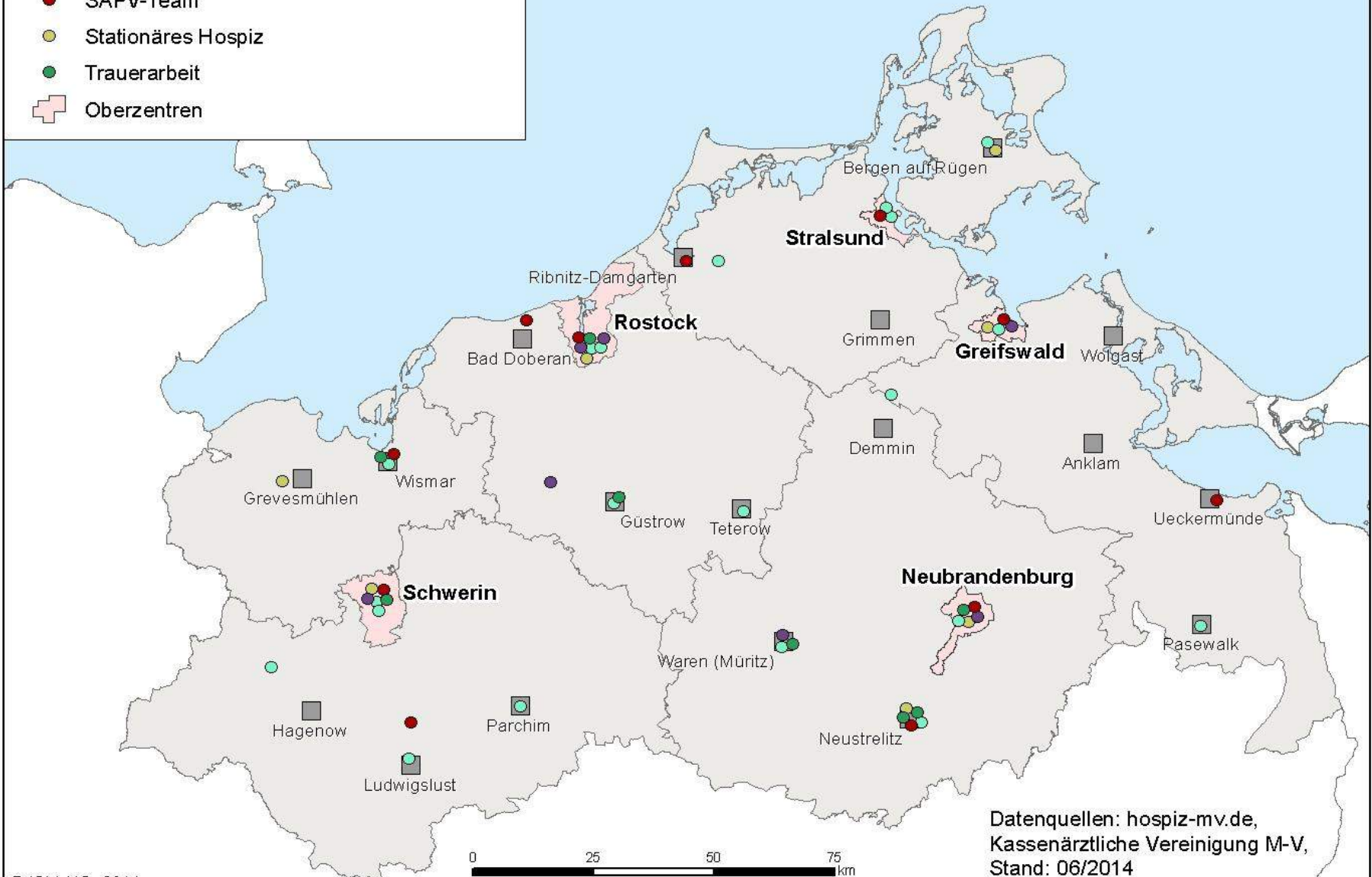
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Datenquelle: Kassenärztliche  
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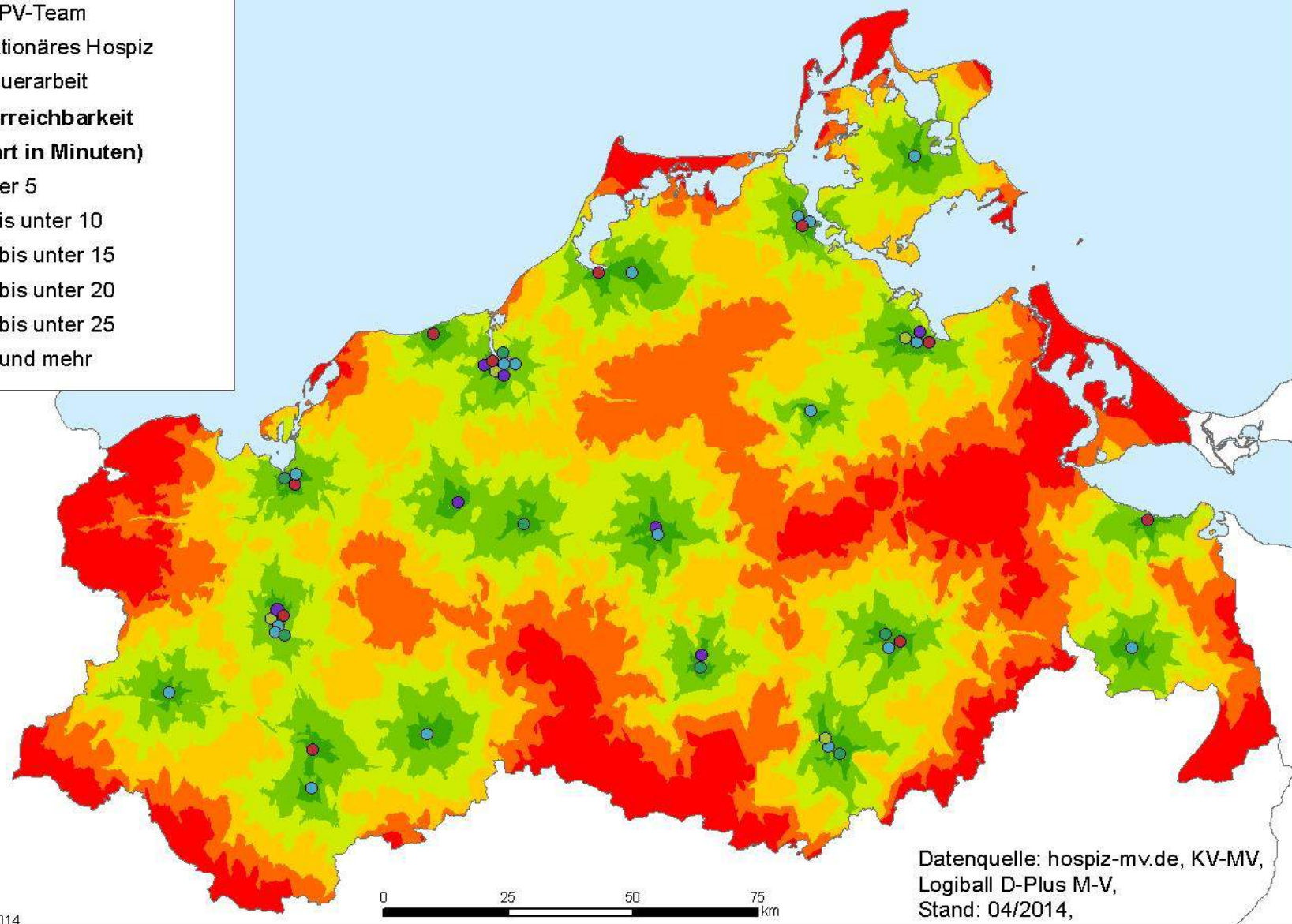


## Palliativversorgung,

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- Stationäres Hospiz
- Trauerarbeit

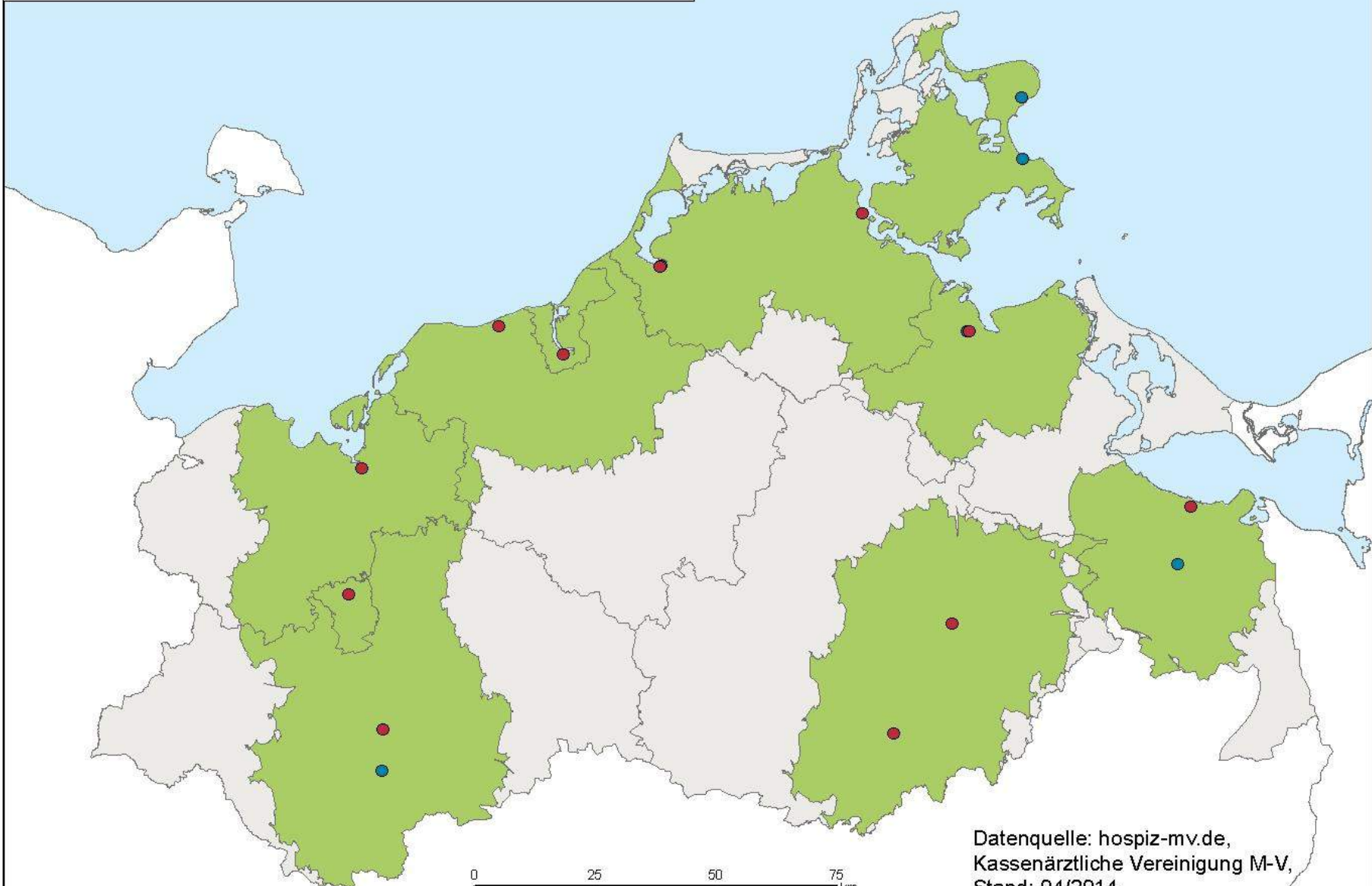
## PKW-Erreichbarkeit (Hinfahrt in Minuten)

- unter 5
- 5 bis unter 10
- 10 bis unter 15
- 15 bis unter 20
- 20 bis unter 25
- 25 und mehr

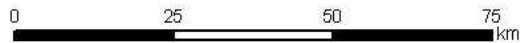


Datenquelle: hospiz-mv.de, KV-MV,  
Logiball D-Plus M-V,  
Stand: 04/2014,

- Sitz SAPV-Team
- Praxis niedergelassener ärztlicher Mitglieder der SAPV-Teams
- 30km Einzugsbereich



Datenquelle: hospiz-mv.de,  
Kassenärztliche Vereinigung M-V,  
Stand: 04/2014



# Telemedicine in outpatient palliative care



## Research questions:

- Can regular telephone calls by qualified nurses serve as an integrated part of adequate outpatient palliative care?
- Is it possible to perform a randomized design in this patient group?

## Intervention:

Regular telephone calls by nurses with a qualification (160 h) in palliative care

Contents of the telephone calls:

- Standardized: assessment of pain and complaints
- Individual: personal, medical, therapeutical, or organizational problems

## Qualification of the palliative care nurses:

- Examined nurses with working experience
- Basic qualification „Palliative Care“ (160h)
- Qualification to use the IT-supported documentation system



**TED:**

**Do palliative patients accept telemedicine as a part of their care ?**



**TED:**

**Do we need a standardized intervention or  
standardized outcome ?**

# Design and methods of the study I



- **Randomized controlled design** (randomization on the patient level)
- **Inclusion criteria:**
  - No need for inpatient care at baseline
  - Outpatient care in the home of the patient is possible
  - Living in the region Western Pomerania
- **Primary outcome:** feasibility and acceptance
- **Secondary outcomes:**
  - Pain
  - Symptoms
  - Quality of life
  - Mobility, activity
  - Physician contacts
  - Hospital admissions

# Design and methods of the study II



**Recruitment** of eligible patients in the pain ambulance of the University Medicine Greifswald

**Baseline assessment:** Computer assisted telephone interviews

Standardized assessment:

- Minimal Documentation System (MIDOS: pain, complaints, need medication)
- Quality of Life (SF-12)
- Karnofsky index (performance status)
- Mobility
- Medication
- Physician contacts, hospital admissions

**Follow up** after three months,  
shorter time period if necessary



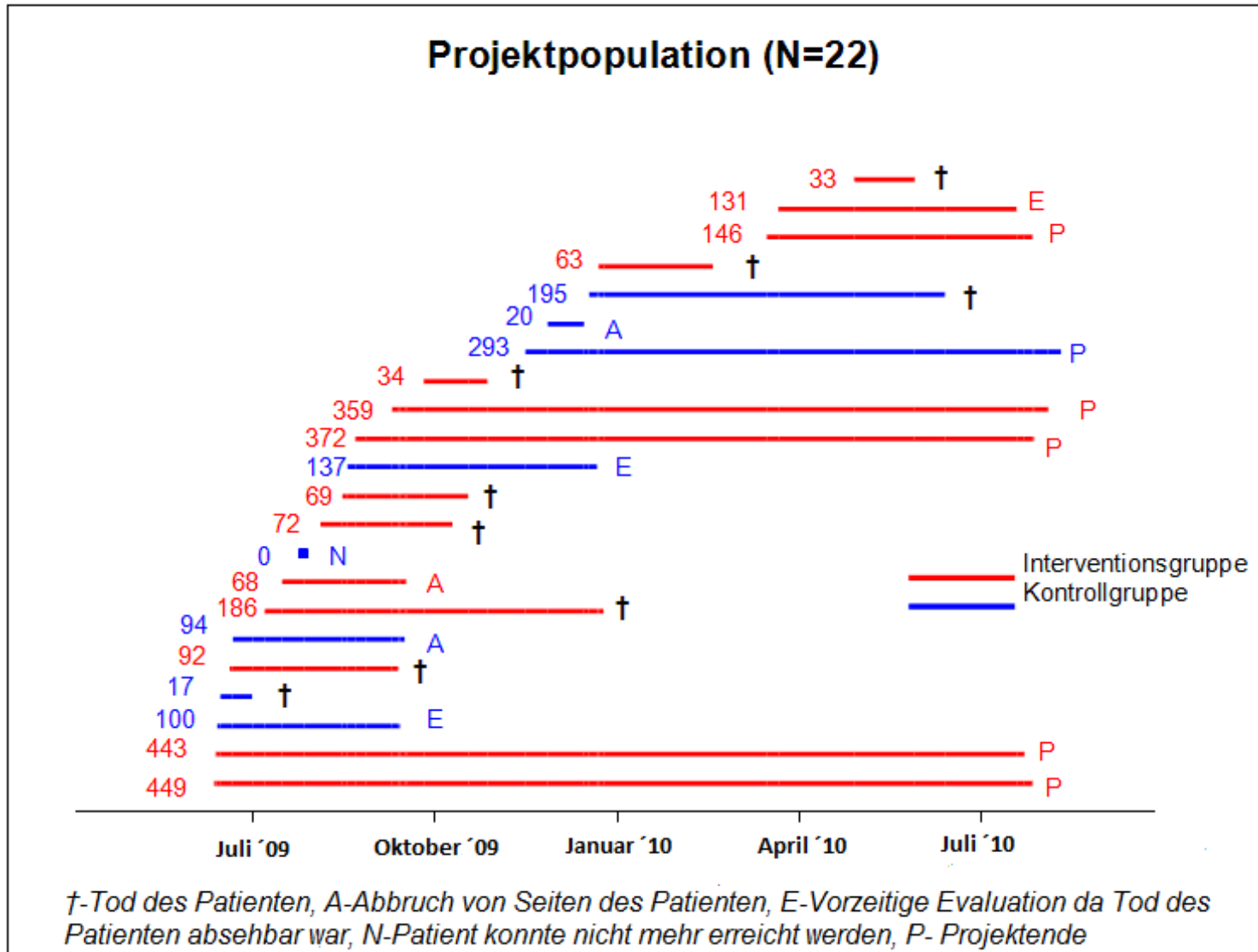


**TED:**

**Is it possible to perform a randomized design in this patient group ?**

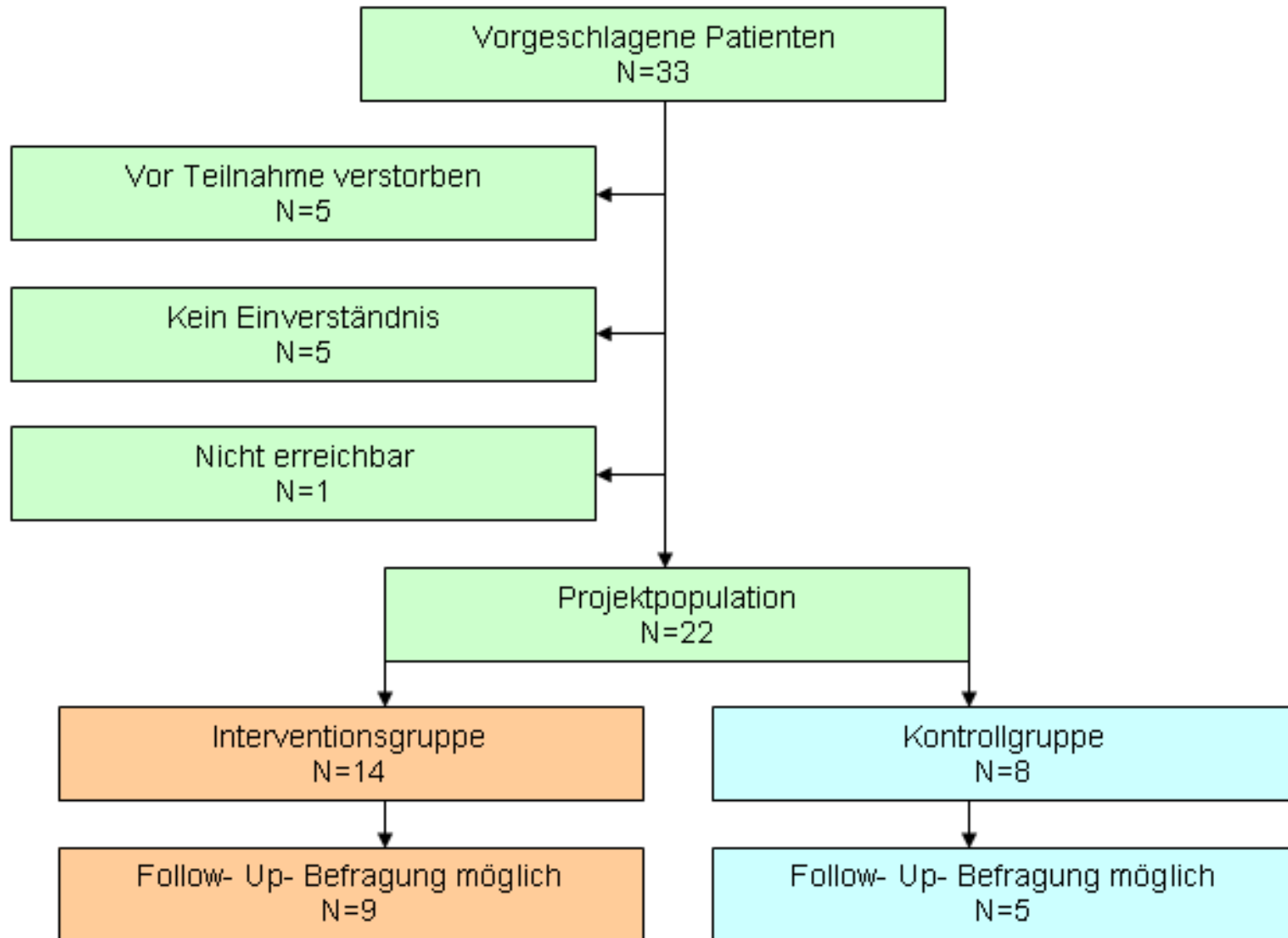


# Time period of the patients in the project



- 13,6 % (N=3) of the patients leaved the project
- One reason (N=1): no power for further home visits

# Flowchart of the project



# Patient characteristics



	Females	Males
IG	57% (N=8)	43% (N=6)
KG	50% (N=4)	50% (N=4)

## Age

	N	MW	Min.	Max
IG	14	62,79	49	77
KG	8	64,63	45	84

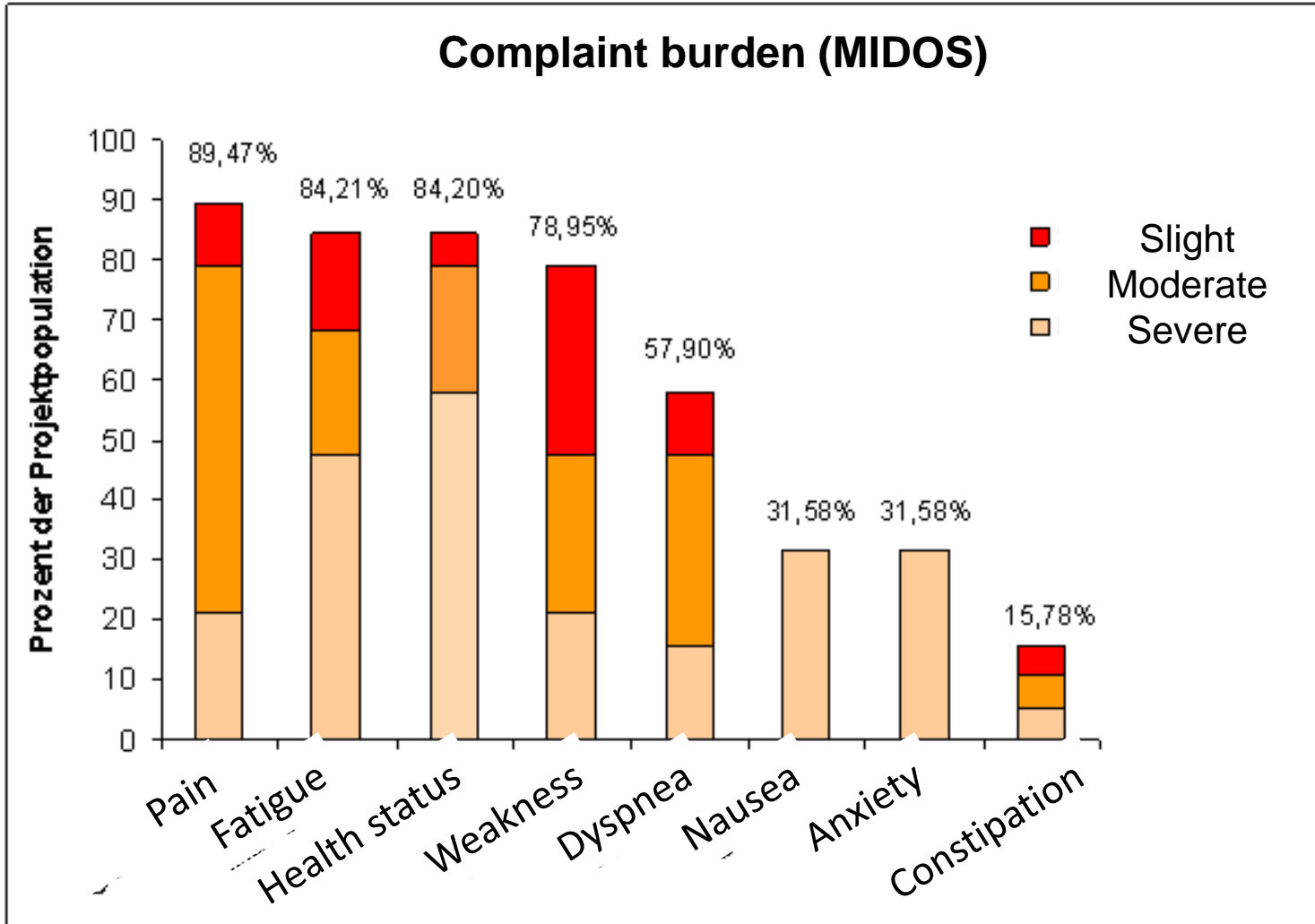
IG: Intervention group

KG: Control group

## Diagnoses

Tumors of lymph nodes and bone marrow	23% (N=5)
Breast cancer	18% (N=4)
Prostate Cancer	14% (N=3)
Colon cancer	14% (N=3)
Head and neck tumors	9% (N=2)
Gynecological tumors	9% (N=2)
kidney cancer	5% (N=1)
Other tumors	9% (N=2)

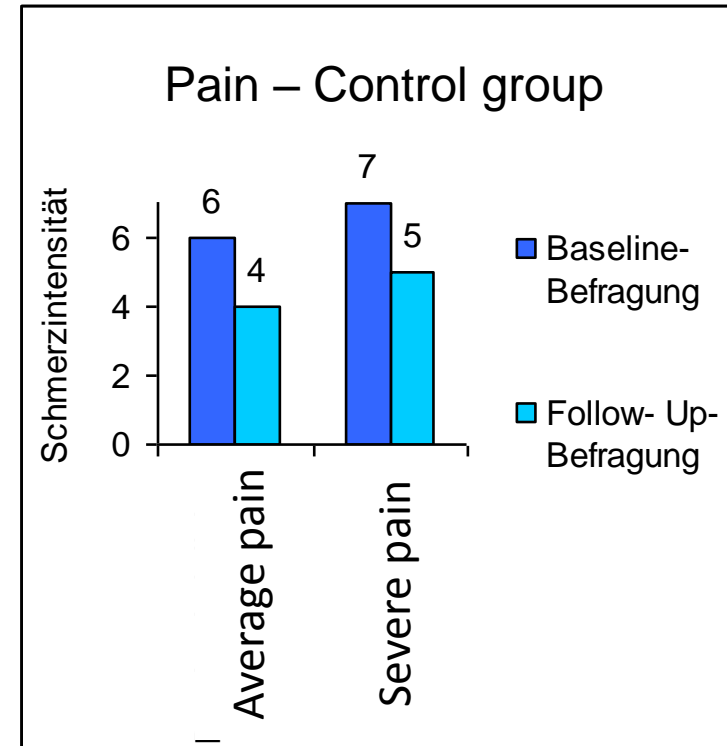
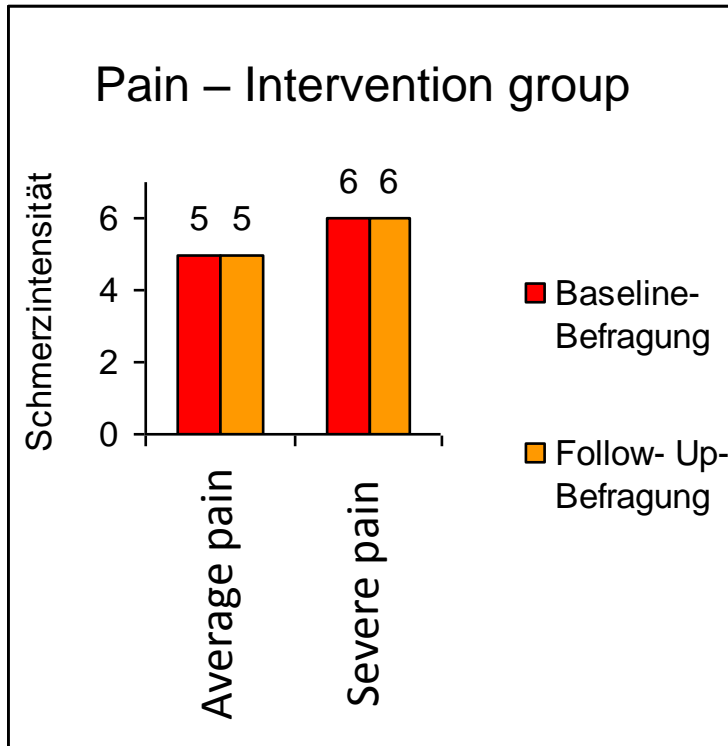
# Baseline analysis



Score of the complaint burden

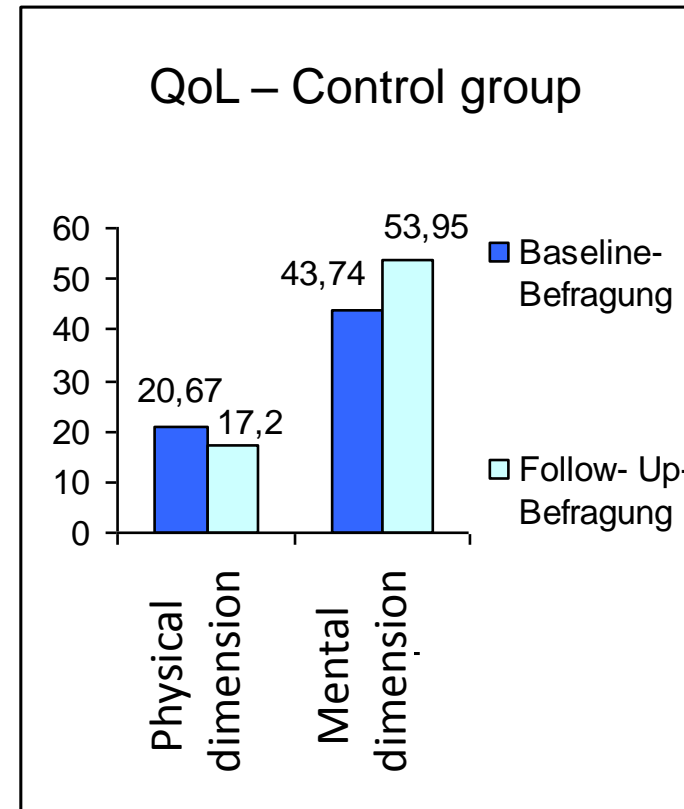
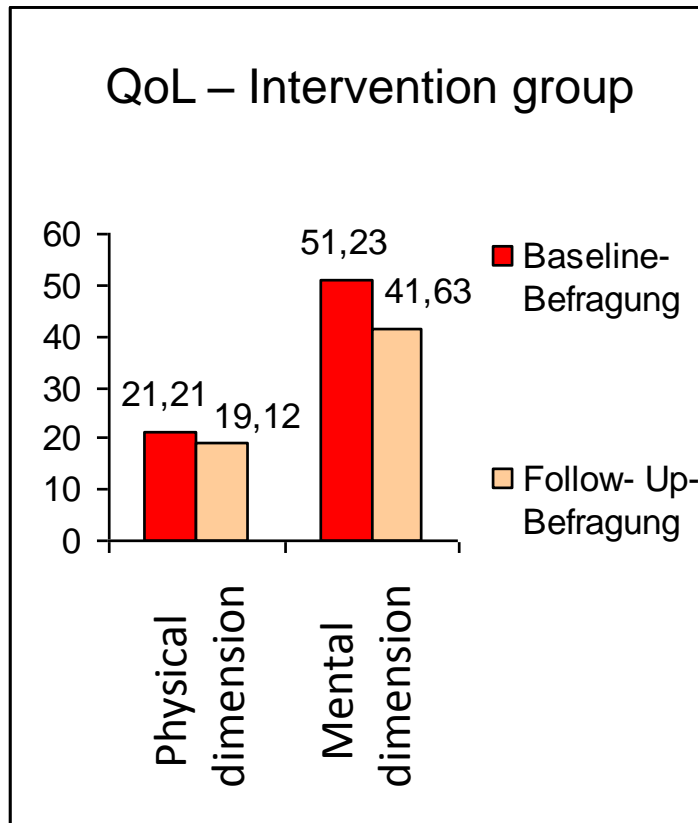


# Patient reported outcomes - pain



No significant difference between the groups at follow-up

# Patient reported outcomes – Quality of life

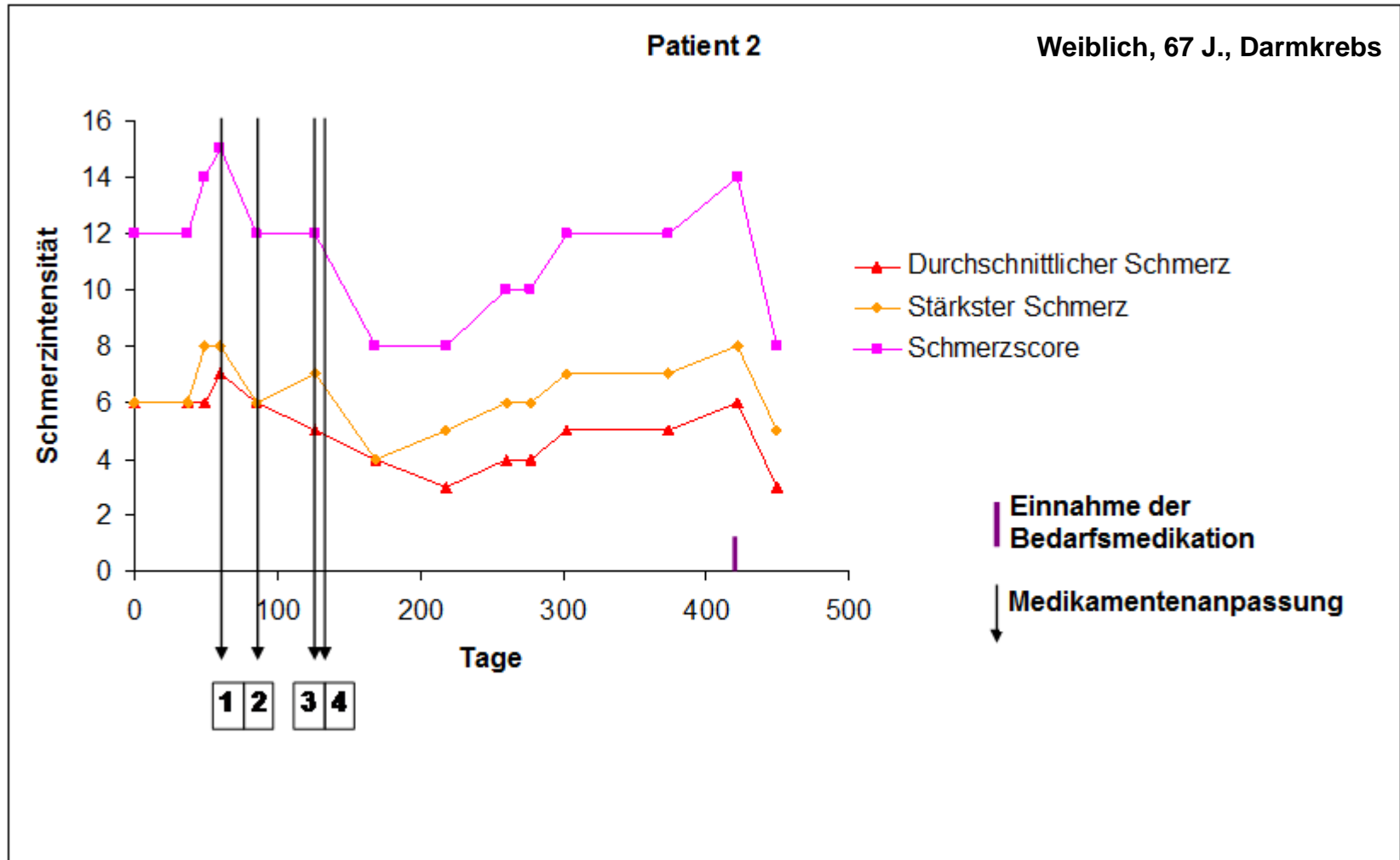


No significant difference between the groups at follow-up

# Patient individual analysis



# Patient individual analysis







## What is your opinion about the telemedical care concept?

• „very good“ N=4	↙ ↘	„Patient is sad, because the project finished.“
• „good“ N=2	→	„Patient was very satisfied, he would have liked to continue“
• „not so good“ N=1	→	„Patient and spouse were satisfied with the project.“
		„The project is pointless because it does not go any further.“

# Discussion and conclusion



Intervention studies in palliative care are difficult:

- Patients die before randomization
- Randomization: N intervention – control group 2:1
- Follow-up is difficult
- The number of patients at follow-up is too small to compare the groups

Positive:

- First data to feasibility and acceptance → Regular telephone calls are a feasible and accepted addition to routine palliative care
- High information density: patient-individual descriptions are possible
- Patient-individual care is possible – also in telemedicine concepts

**Thank you for your attention!**

