

The Danish Palliative Care Database (DPD): research perspectives

Mogens Grønvold

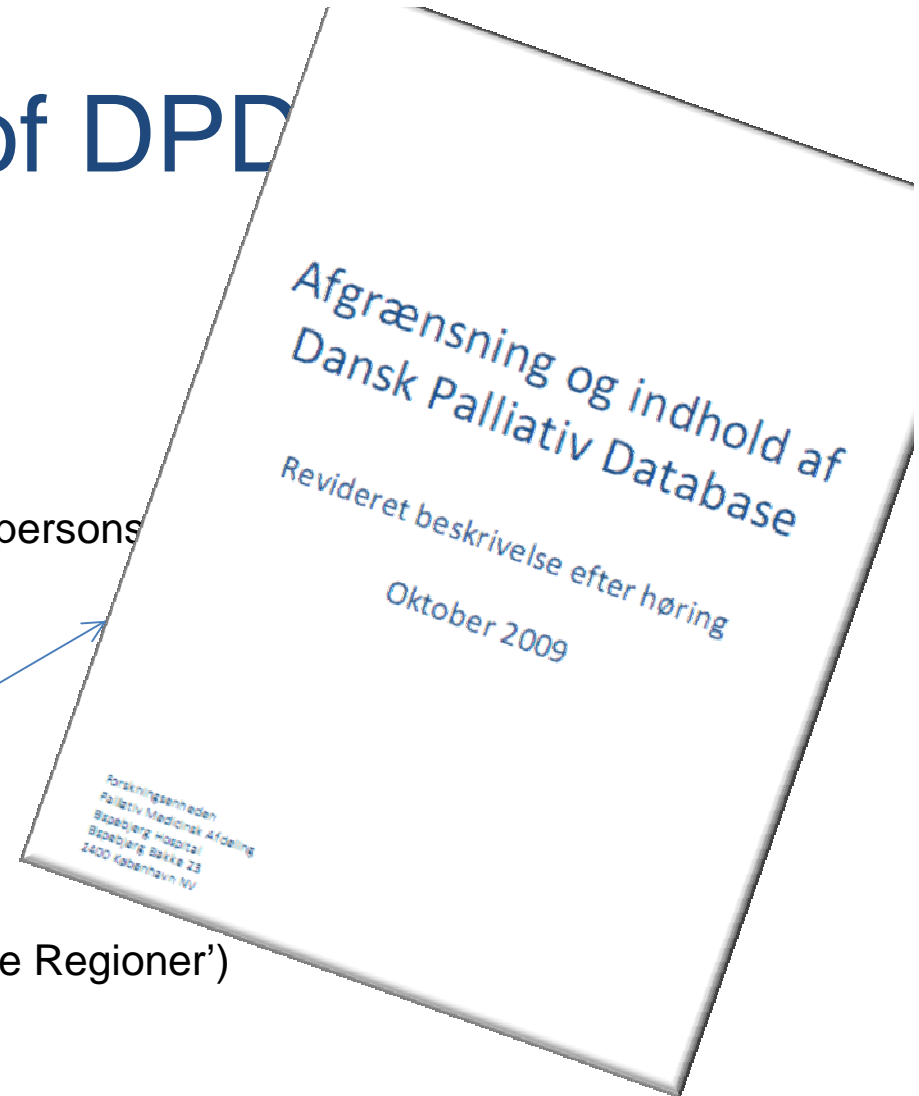
Danish Multidisciplinary Cancer
Group

for Palliative Care

DMCG-PAL

History of DPD

- **2006**
 - Application
- **2007**
 - Grant from Ministry of Health
- **2007-2008**
 - 9 meetings in steering committee (14 persons)
 - Literature review
- **2008**
 - Proposal in public consultation
- **2009**
 - National meeting, revision
 - Approved Danish Board of Health
 - Funding from hospital owners ('Danske Regioner')
- **2010**
 - Opening
- **2011**
 - First report (due in a few weeks)



Aims of DPD

- A **national clinical quality development database** for specialised palliative care
- A **national research database**

DPD inclusion criteria

- All patients referred to specialised palliative care (hospice, palliative care team, palliative care unit) from 1 January 2010
- Each patient registered once per institution
- 'DPD Report 2010':
 - cancer patients only (96%)
 - Patients who were referred AND died in 2010

DPD data sources

1. Web-based reporting from the 36 institutions:
 - Basic clinical and sociodemographic variables
 - Variables about referral, dates start of treatment
 - Multidisciplinary conference
 - EORTC QLQ-C15-PAL at admission

Indtast CPR nr.:

Patient: yy, xx (101010-1..2)
 Kontakt: 01-02-10:

Skema udfyldelse. ✕

< Palliativ database >

Palliativ database

Henvisning

Henvist fra Egen læge Anden palliativ enhed
 Praktiserende speciallæge Patienten selv eller pårørende
 Sygehusafdeling Anden

Diagnose (?)

Dato (modtaget) (?)

Palliativ indsats

Palliativ indsats startet Ja Nej

Dato for start af palliativ indsats

Første kontakt (?) Ambulant Indlæggelse

Afsluttet Som død I live

Socialt

Børn Ingen Børn, mindst et barn under 18 år Børn, alle mindst 18 år

Bopæl Privat Plejehjem/ældrebolig Andet

Tværfaglig konference

Dato for konference

EORTC-skema

EORTC-skema udfyldt Ja Nej - afslag
 Nej - for dårlig Nej - ikke begrundet

1. Kort tur 1 2 3 4 Uoplyst

2. Ligge i sengen 1 2 3 4 Uoplyst

3. Brug for hjælp 1 2 3 4 Uoplyst

4. Ændenød 1 2 3 4 Uoplyst

5. Smerter 1 2 3 4 Uoplyst

6. Søvnbesvær 1 2 3 4 Uoplyst

7. Følt dig svag 1 2 3 4 Uoplyst

8. Savnet appetit 1 2 3 4 Uoplyst

9. Kvalme 1 2 3 4 Uoplyst

10. Forstoppelse 1 2 3 4 Uoplyst

11. Træt 1 2 3 4 Uoplyst

12. Vansk. smerter 1 2 3 4 Uoplyst

13. Ansændt 1 2 3 4 Uoplyst

14. Deprimeret 1 2 3 4 Uoplyst

15. Livskvalitet 1 2 3 4 5 6 7 Uoplyst

Andre symptomer Ja Nej

Udfyldt med hjælp Ja Nej Uoplyst

Dato (EORTC score) (?)

DPD data sources

1. Web-based reporting from the 36 institutions:
 - Basic clinical and sociodemographic variables
 - Variables about referral, dates start of treatment
 - Multidisciplinary conference
 - EORTC QLQ-C30 at admission
2. Register-based data (palliative care activity, etc.)

Results for the year 2010

- 'DPD Report 2010' not yet published, i.e. still preliminary

Dansk Palliativ Database

Årsrapport 2010

Foreløbig udgave 1. juli 2011

DMCG-PAL

DMCG-PAL

Sekretariatet for DMCG-PAL/Dansk Palliativ Database
Forskningsenheden, Palliativ medicinsk afdeling
Bispebjerg Hospital

DPD completeness

- 36/36 specialised palliative care institutions report their patients to DPD
- Validation against the Danish Patient Register: completeness > 95.7%
- Average completeness of DPD variables: 98.6%

Patients 2010

		Referred N (%)
Unique patients		6,041 (100 %)

Patients 2010

		Referred N (%)
Patient courses		7,859 (100 %)
Unique patients		6,041 (100 %)

Patients 2010

	Received N (%)	Not received N (%)	Referred N (%)
Patient courses	5,336 (67.9 %)	2,523 (32.1 %)	7,859 (100 %)
Unique patients	4,241 (70.2 %)	1,800 (29.8 %)	6,041 (100 %)

Survival from referral (days)

	N	Mean	Median
Palliative team/ unit	3.692	48.8	30
Hospice	2.349	30.6	17
All	6.041	41.7	24

EORTC QLQ-C15- PAL scale (0-100)	n	DPD Mean score
<i>Symptom scales (low score good)</i>		
Pain	2,607	59
Dyspnea	2,594	39
Sleeping difficulties	2,591	38
Appetite loss	2,593	62
Constipation	2,565	36
Nausea/vomiting	2,590	29
Fatigue	2,554	79
<i>Function scales (high score good)</i>		
Physical function	2,573	24
Emotional function	2,470	63
Overall quality of life	2,330	37

DPD: Danish Palliative Care Database

DMCG-PAL

EORTC QLQ-C15- PAL scale (0-100)	n	DPD Mean score	KPV* Mean score
<i>Symptom scales (low score good)</i>			
Pain	2,607	59	19
Dyspnea	2,594	39	16
Sleeping difficulties	2,591	38	23
Appetite loss	2,593	62	12
Constipation	2,565	36	12
Nausea/vomiting	2,590	29	6
Fatigue	2,554	79	31
<i>Function scales (high score good)</i>			
Physical function	2,573	24	81
Emotional function	2,470	63	81
Overall quality of life	2,330	37	72

DPD: Danish Palliative Care Database

DMCG-PAL

KPV: KræftPatientens Verden, a cross-sectional survey of 2,245 randomly selected Danish cancer patients in all stages

EORTC QLQ-C15- PAL scale (0-100)	n	DPD Mean score	KPV* Mean score
<i>Symptom scales (low score good)</i>			
Pain	2,607	59	19
Dyspnea	2,594	39	16
Sleeping difficulties	2,591	38	23
Appetite loss	2,593	62	12
Constipation	2,565	36	12
Nausea/vomiting	2,590	29	6
Fatigue	2,554	79	31
<i>Function scales (high score good)</i>			
Physical function	2,573	24	81
Emotional function	2,470	63	81
Overall quality of life	2,330	37	72

DPD: Danish Palliative Care Database

DMCG-PAL

KPV: KræftPatientens Verden, a cross-sectional survey of 2,245 randomly selected Danish cancer patients in all stages

Indicator 1: Proportion of referred, relevant patients who were actually received in specialised palliative care (SPC)

	%	
Capital Region	66	
Region Zealand	88	✓
Region South	71	
Region Mid Jutland	82	✓
Region North Jutland	82	✓
Denmark	77	✓

Standard=75%

Indicator 2: Proportion of patients who waited less than 10 days before admission to SPC

	%	
Capital Region	70	
Region Zealand	86	
Region South	75	
Region Mid Jutland	90	✓
Region North Jutland	88	
Denmark	82	

Standard=90%

Indicator 3: Proportion of patients dying from cancer who were in contact with SPC

	Incidence pr. 100	
Capital Region	21	
Region Zealand	33	
Region South	27	
Region Mid Jutland	31	
Region North Jutland	32	
Denmark	28	

Standard=35%

DMCG-PAL

Indicator 4: Proportion of patients who completed the EORTC QLQ-C15-PAL at admission

	%	
Capital Region	33	
Region Zealand	55	✓
Region South Denmark	63	✓
Region Mid Jutland	62	✓
Region North Jutland	22	
Denmark	49	

Standard=50%

Indicator 5: Proportion of patients discussed at a multidisciplinary conference (with the presence of at least 4 professions)

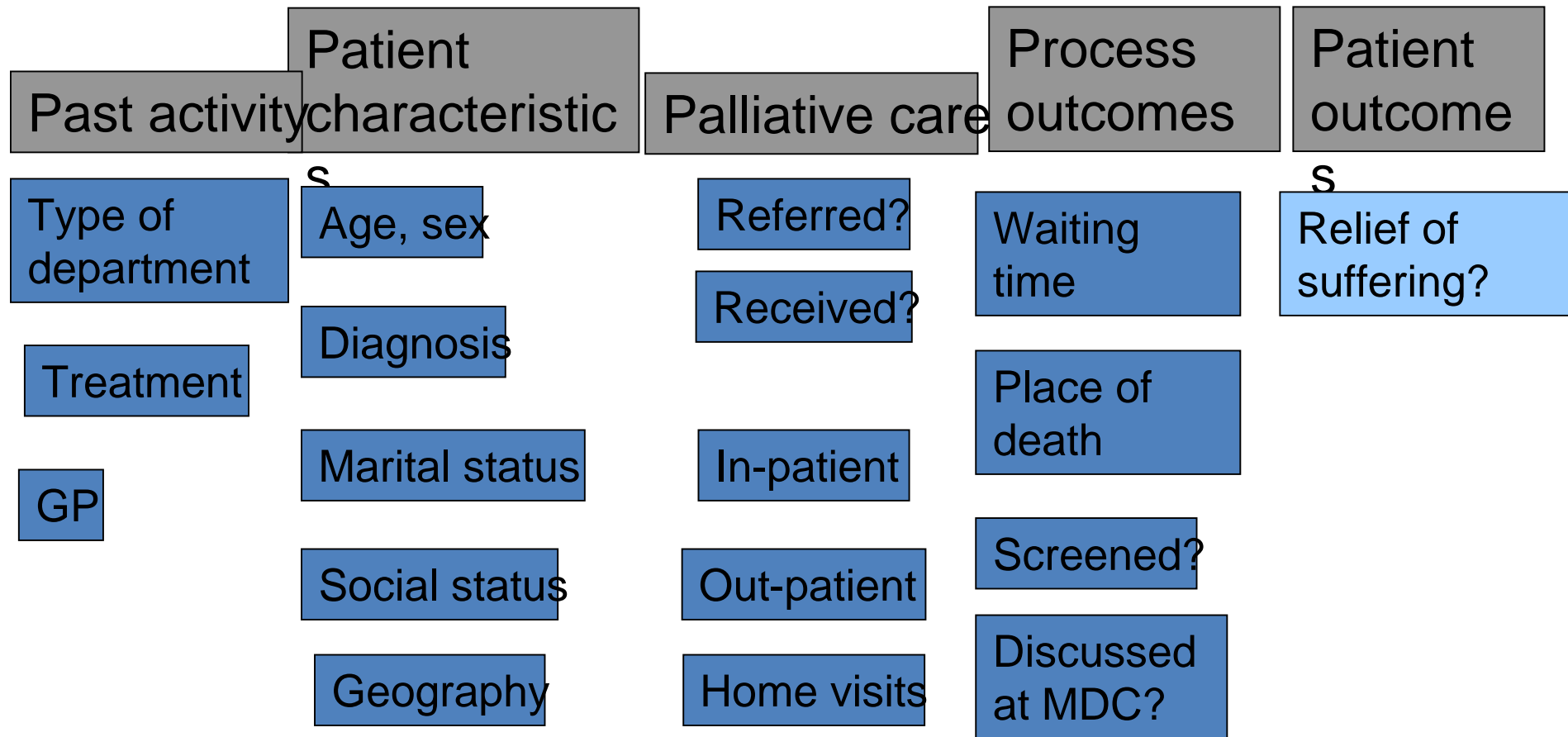
	%	
Capital Region	27	
Region Zealand	34	
Region South Denmark	48	
Region Mid Jutland	37	
Region North Jutland	62	
Denmark	40	

Standard=80%

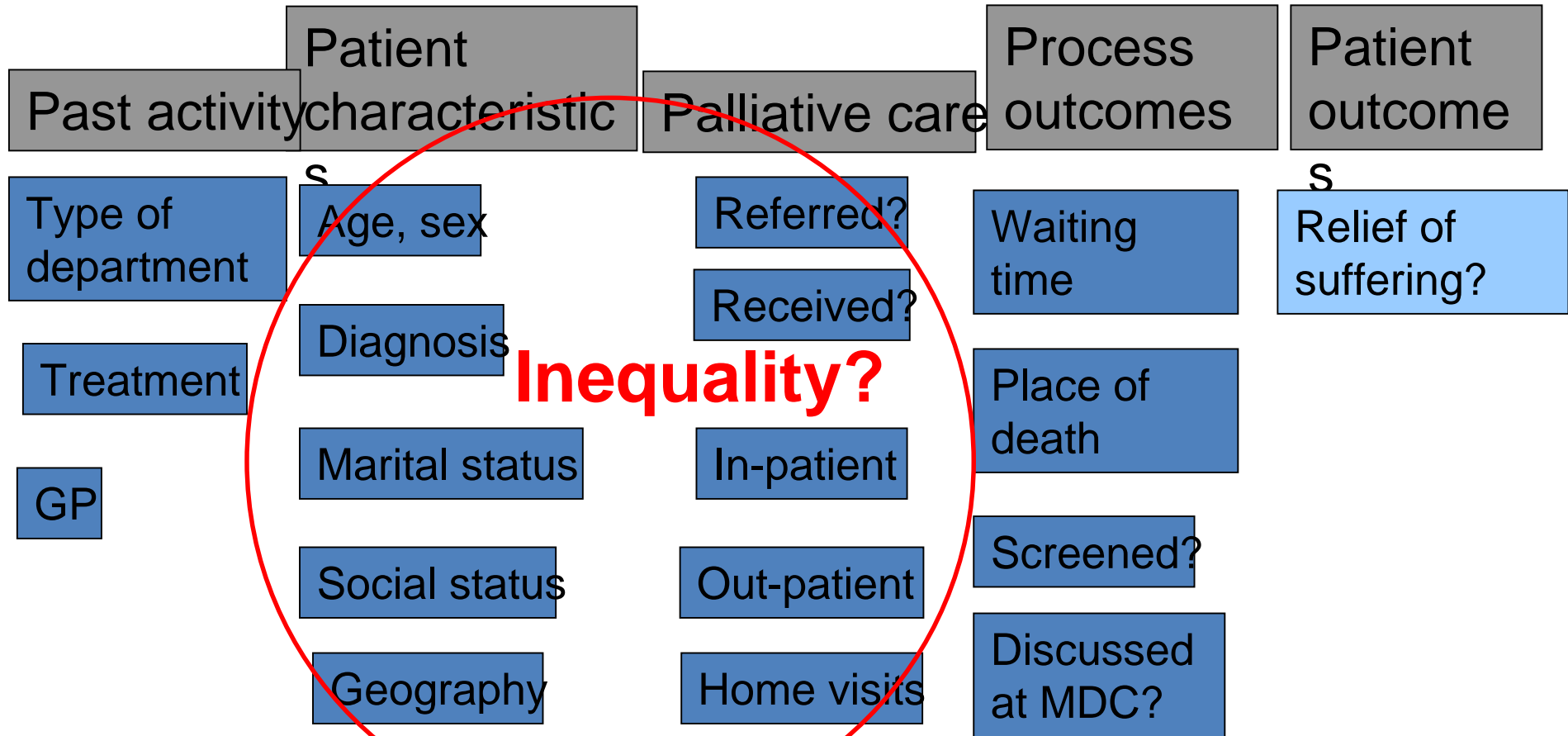
Planned DPD research

- Understanding the relationships between
 - Patient characteristics (sociodemographic and clinical variables, symptomatology)
 - Geographical variations in palliative care (basic and specialised)
 - Quality of care
 - Place of death
 - Effect of palliative care (not yet included)
- Changes in the above over time

What are the relationships?



What are the relationships?



Conclusions

- It proved possible to
 - Obtain consensus about content of a national database
 - Collect complete national data
- First year results
 - 28% of cancer patients got contact with SPC
 - Referred 24 days before death (median)
 - Large regional variation in quality (even larger variation between institutions)
 - Room for improvement
- Excellent basis for health services research