Rehabilitation and Palliative care in Denmark

INTERNATIONAL EXPERTS

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University of Exeter Medical School, England

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Professor of medical sociology
Wellcome Trust Investigator
University of Glasgow, Scotland
Rehabilitation and palliative care
From my heart to cancer and back

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Professor, MD, cardiologist
University of Southern Denmark
Rehabilitation Centre, Beitostølen

1987 - Take off for Oslo

What is taking you so long?

1987  1997  2007  2017

2017 – Opening of centre
Outline of presentation

• From student to medical doctor – from student to researcher (1987)
• Rehabilitation in coronary disease – from evidence to practice (1997)
• Rehabilitation in complex cardiac diseases (2007)
• Rehabilitation and palliative care – future directions (2017)
Health is
"a state of physical, mental, and social well-being and not merely the absence of disease or infirmity (skavanker)."

WHO 1946
Working as student research-assistance

National Institute of Clinical Epidemiology (later National Institute of Public Health)

Finn Kamper Jørgensen
Mette Madsen
Knud Juel

Health service research based on surveys:
- Children's Health at school start
  (68 communities)
- Children's vaccination-program
- Health at the workplace LEGO

Bispebjerg Hospital (Central administration)
WHO - Health promotion hospital

Health service research:
- Re-hospitalisation and Length of stay in medical wards
- Smoke free hospital – smoking cessation

National recommendations
Cardiac rehabilitation

Rehabilitation in coronary heart disease

*From evidence to clinical practice in Denmark*
Clinical presentation of coronary heart disease

- Asperin 300 mg straks
- ADP-receptorblockers
- Heparin 10.000 IE iv.

CAG: LAD stenosis
Acute PCI: 1 vessel disease
Causes of death (2 most common)
agestandardised pr. 100,000 inhabitants

Aproximately coronary heart disease:
Incidence - 14,000 IHD / year (new hospitalisations)
Prevalence – 240,000
Living with coronary heart disease

• CHD is a major cause of death and disability in developed countries with myocardial infarction as one of the main presentations
• Incidence is declining in the western world, but is expected to raise world-wide to 32 million people by 2030

Disabilities
• Loss of physical functioning due to complication to disease, low physical activity level, anxiety to perform exercise
• Mental distress: 20-30% depression – 15-25% anxiety (HADS)
• High risk lifestyle (smoking, dietary habits, low physical activity level)
• Approximately 20-30% leaves the labor market
• Health related quality of life is impaired
Figure 2  The proposed trajectories of dying. Top left, unexpected death is depicted as might be seen when an arrhythmia complicates clinically silent cardiac disease. Top right, the predicted course of someone with an incurable, fatal illness such as widely metastatic lung cancer is projected. Bottom left, the gradual, often unpredictable, decline in function, punctuated by exacerbations, of persons with chronic debilitating illness is shown. Persons with chronic, progressive pulmonary diseases would fit this trajectory best. Bottom right, slowly progressive degenerative disorders such as Alzheimer’s-type dementia and strokes might result in the progressive decline graphed here. From Morrison, Meier with permission.
Outline and terminology

Adapted from Storm et al. Ugeskr læger; 2002;164:2876-81
History of rehabilitation in coronary disease

1950
USA: Exercise training to prevent loss of function due to lengthy hospitalisations

1960
USA: Out-patient phase II exercise training to ensure return to work

1970
Lifestyle intervention and education (Daily physical activity, dietary advice and smoking cessation)

1980
Psychosocial support to meet psychological aspects

1990
Clinical recommendations

2000

2010
Comprehensive rehabilitation
Figure 2. Years of establishment of phase II components of CR services at 53 hospitals in Denmark and average number of years since the component was established (range) based on a questionnaire survey on cardiac rehabilitation services in 1999.

First recommendations in Denmark
Does it have to take so long?

Figure 2
Myocardial Infarction (MI) patients treated with clopidogrel: persistence with clopidogrel treatment during the first year after discharge.

Barriers to adherence to clinical recommendations?

Figure. Barriers to Physician Adherence to Practice Guidelines in Relation to Behavior Change

The DANREHAB trial was initiated in 1999. A large RCT (N=770 patients)
1998 - A 5 days residential rehabilitation stay formed the basis for Development of the DANREHAB 6 weeks out-patient program
Cardiac rehabilitation
6 weeks out-patient program

Complex intervention
Colleges' statements on Rehabilitation
Not for cardiologists

Nurse – religion

PCI surgeon – only for 'losers' not able to do anything else

Cardiologist – senior consultant

Hmm.. I do the operation – The patient will be perfectly well!

Cardiac surgeon – we include the topic due to political reasons

Teaching cardiologist – who will man 'The coffee club'

Cardiologist – responsible for the manning
Register-based 3 years follow-up

**Composite outcome measure**

Hazard ratio = 0.92
95% CI (0.75–1.13)
P = 0.40

*Death, myocardial infarction, acute first time re-admission due to heart disease which ever came first*
Length-of-stay (LOS) – cost saving intervention

Register-based 3 years follow-up

**Total Length-of-stay (all admissions)**

<table>
<thead>
<tr>
<th>LOS</th>
<th>UC</th>
<th>CR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>9.099</td>
<td>6.847</td>
</tr>
<tr>
<td>Range</td>
<td>(1–217)</td>
<td>(1–94)</td>
</tr>
<tr>
<td>Mean</td>
<td>6.2</td>
<td>5.4</td>
</tr>
</tbody>
</table>

Reduction 25%

Zwisler et al. ESC, 2008
Patient satisfied – however no effect on HRQL

How satisfied have you been with the follow-up services offered within the past 12 months?

[Cardiac rehabilitation – a health technology assessment]. National Board of Health, Denmark, 2006
Treatment rationale and outcome in rehabilitation
Focus on quality of life

Initiated studies – Region Sjælland and Holbæk sygehus

Development and validation on HeartQol core-disease questionnaire
Hospital anxiety and depression scale HADS
Prevention of re-hospitalisation, Psychosocial support
Quality of life in haematological cancer with focus on MPN
From guidelines to clinical practice in coronary disease

1997
- The DANREHAB trial (Heart Foundation)

2000
- Initiation of clinical database (DCS Working group)

2005
- National Clinical Guidelines (National Board of Health)
- Clinical database running

2007
- Health Technology assessment (National Board of Health)

2013
- National recommendations (Heart foundation and Ministry of Health)

2017
- The DANREHAB trial (Heart Foundation)
Quality assurance in rehabilitation

Figure 1. The quality of care continuum in cardiac rehabilitation. Adapted with permission from the EuroHeart Survey Programme.

Zwisler et al. EJCP, 2011
<table>
<thead>
<tr>
<th>Goal</th>
<th>Achieved</th>
<th>%</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1a: Deltagelse</strong></td>
<td>35</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td><strong>1b: Vedholdende deltagere</strong></td>
<td>75</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td><strong>2a: 80% af træningssessioner</strong></td>
<td>70</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td><strong>2b: 10% stigning funktionstest</strong></td>
<td>80</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td><strong>3: Rygestop</strong></td>
<td>60</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td><strong>4: Diætbehandling</strong></td>
<td>***</td>
<td>***</td>
<td></td>
</tr>
<tr>
<td><strong>5: Reduktion af LDL kolesterol</strong></td>
<td>60</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td><strong>6: Blodtryk</strong></td>
<td>70</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td><strong>7: Screening for diabetes</strong></td>
<td>90</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td><strong>8: Screening for depression</strong></td>
<td>80</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td><strong>9: Antitrombotisk behandling</strong></td>
<td>95</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td><strong>10: Statinbehandling</strong></td>
<td>80</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td><strong>11: Betablokadebehandling</strong></td>
<td>80</td>
<td>Yes</td>
<td></td>
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</tbody>
</table>

Danish Cardiac rehabilitation Database (DHRD)

Not available for public
Cardiac Rehabilitation from Denmark going global

In Denmark, more than 10,000 people per year have acute myocardial infarction, about 200,000 people have ischaemic heart disease and many people are at high risk of developing heart disease. Despite substantially improved treatment services, heart disease continues to cause great human suffering.

There is solid evidence that comprehensive cardiac rehabilitation improves patients’ quality of life and reduces morbidity and mortality. Nevertheless, only one third of Denmark’s hospitals offer comprehensive cardiac rehabilitation, and less than 10% of Denmark’s patients with heart disease are offered these services.

This book is a practical manual on organizing and developing a hospital-based cardiac rehabilitation programme. The book describes how the comprehensive cardiac rehabilitation programme at Bispebjerg Hospital is currently organized and provides several specific action plans and tools.

The target group is health care professionals and health planners in the fields of cardiac care or rehabilitation.
FIGURE. World map denoting low- and middle-income countries where cardiac rehabilitation is known to be offered based on English peer-reviewed publications and grey literature.
Rehabilitation in complex cardiac diseases

The CopenHeart trials

Research question: Can recommendations for specific diseases i.e. CHD be transferred to other cardiac conditions?
Sexual dysfunction
Organisation, Economic og user-perspective
Exercise and Quality of life
The CopenHeart Trials
Mixed methods

- Cochrane review
- QUAN: Survey register-based pre-study
- QUAL: before intervention: Pre-study
- Organisation: Economic evaluation
- Randomised Control Trial
  - QUAN
  - Intervention
  - QUAN
- Mechanistic studies
- Economic evaluation
- QUAN
- QUAL: post measure
- Final interpretation based on QUAN and QUAL results

2007 – 2017
**Mode of delivery**

**Rigshospitalet – psychoeducation + initiation of exercise training**

*Then by choice:*

- Home-based training
- Local setting community or hospital

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*21 communities participate in CopenHeart*
The CopenHeart Team and partners

Hjertecenteret, Rigshospitalet
Gentofte Hospital, Kardiologisk afdeling P Roskilde sygehus, Kardiologisk afdeling Region Sjælland
CopenHearts kommunale træningscentre og samarbejds-sygehuse/hospitaler
Statens Institut for Folkesundhed, SDU CTU, Rigshospitalet CopenRehab, KU
PH Metropol REHPA

1 PostDoc, 6 PhD Thesis, 5 masterproject

CorusFit, Vertic
The CopenHeart Trials

Organisation, Economic og user-perspective

Sexual dysfunction

Exercise and Quality of life

= 827 patients enrolled
Rehabilitation and palliative care
REHPA
Future directions?

2017 and beyond
Rehabilitation and palliative care on the national budget

Improving cancer care trajectory - 2012

Overall aim of the centre

• To strengthen clinical research in rehabilitation and palliation

• To ensure that research is transferred rapidly into cross-professional and cross-sectorial clinical practice to the benefits of patients and society
<table>
<thead>
<tr>
<th>Year</th>
<th>Clinical Practice Area</th>
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<tbody>
<tr>
<td>2012</td>
<td>Research in clinical practice</td>
</tr>
<tr>
<td></td>
<td>Cancer rehabilitation and palliative care</td>
</tr>
<tr>
<td>2017</td>
<td>Pulmonary rehabilitation and palliative care</td>
</tr>
</tbody>
</table>

**Generic topics and aspects of interests**

**Cancer and other diseases with high mortality**

**Research in clinical practice**

**Cardiac rehabilitation and palliative care**
Current topics to address across diagnosis

- How to integrate rehabilitation and palliative care
- Content and delivery of across sectors
- Needs assessment? Intervention for all or only some patients?
- What is the proper outcomes of rehabilitation
- Spouse involvement and interventions
- Patient and public involvement (PPI)
- Patient Reported Outcomes (PRO)
- Quality assurance
- How to reach vulnerable patients? I.e. migrants, social inequity
- Rehabilitation and palliative care in low and middle-income countries
- Many, many more questions needs to be adressed
Rehabilitation Centre, Beitostølen

1987 - Take off for Oslo

Collaboration and support

We support you

REHPA

2017 – Opening of centre
Dedicated collaborators - dear colleges

DIKE – nu SIF

Bispebjerg hospital

Rigshospitalet

Afdeling R

Odense universitetshospital

CopenRehab

DSI – nu KORA

DCS

Kliniske diætister

Hjerteforeningen

Danske fysioterapeuter

1997 2007 2017

Ibrahim Cardiac Hospital Dahka, Bangaldesh

Region Sjælland

Herlev sygehus

6 kommune samarbejdet

Sundhedsministeriet/SST

KL

DEFACTUM

Kræftens Bekæmpelse

Hjerteforeningen

DSR

Danske fysioterapeuter

Kliniske diætister

PH Metropol

Ibrahim

Cardiac

Hospital

Dahka, Bangaldesh

Cloud and UNIVERSE

REHPA
Det hele menneske