Knowledge about Palliative Care
- mapping, user involvement (and development of practice)

International Observatory on End of Life Care.
Research seminar
19th November 2015

Helle Timm, professor, head of the Danish Knowledge Centre for Rehabilitation and Palliative Care
Knowledge Centre and knowledge
The Knowledge Centre of Rehabilitation and Palliative Care

- The Danish Knowledge Centre of Palliative Care (PAVI), 2009 – 2013
- The Danish Knowledge Centre of Rehabilitation and Palliative Care (REHPA), 2014 –

- The purpose of the national centre is to gather, to produce/construct and to share knowledge about rehabilitation and palliative care for people suffering from life threatening diseases
- Target groups; mainly professionals, but also lay-people, civil servants, politicians etc.
- Publically financed, part of the University of Southern Denmark, situated in Copenhagen and Nyborg, Funen
# The way, we work

<table>
<thead>
<tr>
<th>Mappings - of services and knowledge</th>
<th>Research and development - rehabilitation and PC</th>
<th>Communication and dialog</th>
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<tbody>
<tr>
<td>• Mappings of services</td>
<td>• Intervention research</td>
<td>• Professional-, research-, citizens and media-related</td>
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<tr>
<td>- Descriptive (surveys)</td>
<td>- RCT</td>
<td>- Publications</td>
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<td>- Explorative (interviews, observations)</td>
<td>- Action research</td>
<td>- Websides</td>
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<td>• Litteratur studies and reviews</td>
<td>- Development projects</td>
<td>- Presentations, education</td>
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<td>- Evaluations</td>
<td>- Arrangement of konferences, seminars, workshops</td>
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<td>• Register studies</td>
<td>- Networking, boards</td>
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<td>- Press</td>
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<td>- Information, flyers</td>
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Cancer rehabilitation program – in Nyborg
<table>
<thead>
<tr>
<th>Mode 1</th>
<th>Mode 2</th>
<th>Mode 3</th>
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<tbody>
<tr>
<td>Defined by researchers</td>
<td>Defined by users</td>
<td>Defined by political/governmen-tal strategies</td>
</tr>
<tr>
<td>Hierarchical diffusion</td>
<td>Social diffusion</td>
<td>Commercial established</td>
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<tr>
<td>Oriented towards scientific knowledge</td>
<td>Oriented towards the use in society</td>
<td>Oriented towards evaluation, documentation</td>
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<td>Disciplinary organization</td>
<td>Trans-disciplinarity</td>
<td>Monoparadigmatic dominated</td>
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Mapping
On mapping palliative care (PC) - and ranking the quality of PC

- The Economist Intelligence Unit 2015: DK No 19 out of 80 countries
- WPCA/WHO 2014: Global Atlas of Palliative Care at the End of Life
- Centeno et al, 2013: EAPC Atlas of Palliative Care i Europe 2013
- The Economist Intelligence Unit 2010: DK No 22 out of 40 countries
- EU rapport 2003: DK No 13 out of 52 countries
- EAPC White Paper 2009 + 2010
Purposes and challenges in mapping PC

"...to categorize hospice-palliative care
development, country by country,
throughout the world, and then depict
this development in a series of world and
regional maps."

(Wright et al, 2008)

• Absence and quality of data?
• Counting by type of service or by providers?
• The quality of care, the cultural, social and economical meaning and context of care?
References

The purposes and outcomes of mapping PC?

- Policy making – how is it working (in what sense)?
- Measuring quality of PC – how is it working (in what sense)?
User involvement
On user involvement (background)

• In a historical perspective
• As a concept and as methods
• In the our centre
User involvement historically, as a concept and as methods (why, how and where)

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<tbody>
<tr>
<td>Radical/critical</td>
<td>Conflict of interests, inequality in power</td>
<td>Empowerment of users</td>
<td>Macro, meso and micro level</td>
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<tr>
<td>Philosophical/Phenomenological</td>
<td>Differences in perspectives</td>
<td>Exploration of and collaboration from the users’ perspective</td>
<td>Meso and micro level</td>
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<tr>
<td>Concensus, policy making</td>
<td>Democracy/voice</td>
<td>Evaluation Opinion surveys satisfaction surveys</td>
<td>Meso and micro level</td>
</tr>
<tr>
<td>Consensus, policy making</td>
<td>Consumerism/choice</td>
<td>Dissemination of professional knowledge, sharing informations, PROMS</td>
<td>Meso and micro level</td>
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11/20/2015
User involvement in the field of palliative care

• A radical and critical approach?
• A philosophical approach?
• A democratic approach?
• A consumer approach?
Sharing knowledge with Danish Citizens and Patient Organizations (theoretical assumptions)

- Knowledge is transformed/constructed information, therefore knowledge is always grounded in a specific perspective.
- The construction of knowledge has to do with methods (e.g. methods for investigating suffering, palliation or quality of life).
- Knowledge is connected to power.
- For empowerment, for using a voice and for making a choice – you need to know about the options for care.
- To share knowledge with the public, the centre needed a baseline.
- Macro (society and population) and meso level (organisations and units) – while normally in the field the meso and micro level (individuals).
Sharing knowledge with Danish Citizens, and Patient Organizations (intro)

1. The Citizen Project 2012-2013: What do the Danes know about life threatening diseases (LD), death and dying – and do they want to know more?

2. The Knowledge Sharing Project 2013 – 2015: How do Danish patient organizations (PO) communicate about palliative care and how can this communication be developed?

3. The mourning support project (elderly spouses) 2013 – 2015: Sharing knowledge about new mourning theory and the experiences of elderly spouses – with the public, the professionals and a group of spouses.
Sharing knowledge with Danish Citizens and Patient Organizations (definitions)

- **Knowledge** = all kinds of information, that has been “...processed or systematized by thought” (Peter Burke, A Social History of Knowledge, 2000, p. 11)
- **Sharing** = exchanging in person and/or disseminating (knowledge) by means of communication
- **Citizens** = all Danes and the public, but mainly lay-people in general and patients and relatives in particular
- **Patient Organisations** = Private organisations, associations/NGOs concerned with the situation of patients and relatives living with life threatening diseases
- **User involvement** =
# Sharing knowledge with Danish Citizens and Patient Organizations (what did we do?)

<table>
<thead>
<tr>
<th>Project</th>
<th>Methods , purpose and results</th>
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</table>
| **1. The Citizen Project**  | • A survey (baseline 1; what do the Danes know already?)  
• A web-site (sharing knowledge)  
• A workshop (sharing knowledge)                                                                                                                                      |
| **2. The Knowledge Sharing Project** | • A literature search (investigating international experiences)  
• Interviews (baseline 2; how do PO share knowledge about PC?)  
• A network (POs sharing and developing knowledge and communication about PC)  
• Texts and articles for web-sites and the press  
• A course at The Public University  
• A report, an article                                                                                                                    |
| **3. The Mourning Support Project** | • A book  
• A strategy and activities ensuring public awareness/PR                                                                                                                                                     |
The Citizen Project 2012-2013: *What do the Danes know about life threatening diseases (LD), death and dying – and what do they want to know more about? (baseline 1: A survey, 51% of 2000 Danes)*

<table>
<thead>
<tr>
<th>Statements</th>
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<tbody>
<tr>
<td><strong>• LD, death and dying is part of most grown-ups’ lives</strong></td>
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<td><strong>• Death and dying is seen as private but not as a taboo</strong></td>
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<td><strong>• The Danes have relevant knowledge about LD and places of death, but wish different for themselves</strong></td>
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<td><strong>• The Danes have some trust in being taking care of in a physical sense by the Health Care System</strong></td>
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<td><strong>• The Danes worry about LD</strong></td>
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<td><strong>• They want quality before a longer life span</strong></td>
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<td><strong>• They might want the possibility of eutanasia</strong></td>
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<td><strong>• They do not want more knowledge – until they actually need it</strong></td>
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<td><strong>• They think PO can be supportive</strong></td>
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The Citizen Project 2012-2013: *What do the Danes know about life threatening diseases, death and dying – and what do they want to know more about?*

The web-site

The workshop
The Knowledge Sharing Project 2014 – 2015: *How do Danish patient organizations share knowledge about palliative care with their members and how can this communication be improved? (baseline 2: Interviews with POs)*

15 persons:
- 5 chairmen/heads (individual)
- 6 consultants (focus-group)
- 4 patients & relatives (focus-group)

Questions:
- The Danish national strategy of PC (2011)?
- What is PC?
- How do you work with PC in your PO?
- Not much knowledge about the national strategy
- PC = terminal care for cancer patients
- PC = death
- Talking about PC = takes away hope

20-11-2015
Palliative care, patient organisations and hope

"...you do not want to frighten them (the patients). You want them in (to the PO), and you get them in, if you can give them some hope in relation to the disease."
(consultant from PO)
The Knowledge Sharing Project 2014 – 2015: How do Danish patient organizations share knowledge about palliative care with their members and how can this communication be improved?

A network

A "common cause”

- A strategy for making knowledge about palliative care "a common cause”
- Press – media
- Websites of the POs
The Knowledge Sharing Project 2014 – 2015: How do Danish patient organizations share knowledge about palliative care with their members and how can this communication be improved (international experiences)?

A literature search

- Dying Matters, UK (2009-)
- The Conversation Project, US (2010 -)
- Palliative Care, Australia (1991-)

Inspiration for "a common cause"

- Sharing knowledge, disseminating information
- Web-sites
- Awareness week, hundreds of local events (May)
- Storytelling about death & dying, guides
- Death over Dinner (January)
- PC week (May)
Results and conclusion

• Baseline 1 – the survey
• Baseline 2 – the interviews
• Dialog and communication
• More knowledge available on web-sites, in the media, in education etc.
• In process and in progress
• This was a way to do it
• What’s next???

20-11-2015
User involvement within the field of palliative care in general?

<table>
<thead>
<tr>
<th>What is user involvement about in PC?</th>
<th>Which methods and tools should be used?</th>
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<tbody>
<tr>
<td>• Talking, listening and being together?</td>
<td>• Time, space and social relations?</td>
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<tr>
<td>• Sharing knowledge, planning and making decisions?</td>
<td>• Shared decision making, Advance Care Planning</td>
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<tr>
<td>• Evaluating the results of the care given?</td>
<td>• Patient Related Outcome Measures (PROMs)? (EORTC etc?)</td>
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<tr>
<td>• Quality of life?</td>
<td>• Documenting outcomes AND/OR meaning of PC?!</td>
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<td>• Governance?</td>
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Which methods and tools should be used?

- Time, space and social relations?
- Shared decision making, Advance Care Planning
- Patient Related Outcome Measures (PROMs)? (EORTC etc?)
- Documenting outcomes AND/OR meaning of PC?!