Palliative care research in the primary care sector

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Organisation

Aarhus University Hospital:
- The Department of Oncology
- The Palliative Team

Aarhus University:
- The Research Unit for General Practice
- The Research Centre for Cancer Diagnosis in Primary Care
Primary care sector

Palliative team
Specialist Palliative Care Team (40%)

All deceased cancer patients (100%)

Neergaard et al. Unpublished data. 2011
Neergaard et al. Unpublished data. 2011
Studies at a glance...
Patients’ preferred place of death
Place of death
### Patients’ preferred place of death

<table>
<thead>
<tr>
<th></th>
<th>Neergaard et al</th>
<th>Brogaard et al</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>In the beginning of the palliative period (n (%))</td>
<td>At time of inclusion (n (%))</td>
</tr>
<tr>
<td>Home</td>
<td>92 (80.7)</td>
<td>40 (71.4)</td>
</tr>
<tr>
<td>Nursing home</td>
<td>4 (3.5)</td>
<td>1 (1.8)</td>
</tr>
<tr>
<td>Home of relatives</td>
<td>7 (6.14)</td>
<td>-</td>
</tr>
<tr>
<td>Hospital</td>
<td>7 (6.1)</td>
<td>2 (3.6)</td>
</tr>
<tr>
<td>Hospice</td>
<td>1 (0.9)</td>
<td>13 (23.2)</td>
</tr>
<tr>
<td>Other</td>
<td>3 (2.6)</td>
<td>-</td>
</tr>
<tr>
<td>In all</td>
<td>114 (100.0)</td>
<td>56 (100.0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>At the end of the palliative period (n (%))</th>
<th>One month after inclusion (n (%))</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>74 (64.4)</td>
<td>29 (64.4)</td>
</tr>
<tr>
<td>Nursing home</td>
<td>7 (6.1)</td>
<td>-</td>
</tr>
<tr>
<td>Home of relatives</td>
<td>14 (12.2)</td>
<td>-</td>
</tr>
<tr>
<td>Hospital</td>
<td>12 (10.4)</td>
<td>3 (6.7)</td>
</tr>
<tr>
<td>Hospice</td>
<td>4 (3.5)</td>
<td>13 (28.9)</td>
</tr>
<tr>
<td>Other</td>
<td>4 (3.5)</td>
<td>-</td>
</tr>
<tr>
<td>In all</td>
<td>115 (100.0)</td>
<td>45 (100.0)</td>
</tr>
</tbody>
</table>

**Brogaard T**, Neergaard MA, Olesen F, Jensen AB. *Congruence between preferred and actual place of care and death among Danish cancer patients*. Submitted. 2010

Somethings is rotten…

- Prior studies has insinuated that the low percentage of home deaths may be rooted in poor delivery of primary health care

Grande et al. Valued aspects of primary palliative care: content analysis of bereaved carers’ descriptions. Br J Gen Pract 2004
Despite of this, satisfaction with GPs and Community nurses are still rated high of both patients and relatives.

Hanratty B. Palliative care provided by GPs, the carer’s viewpoint. Br J Gen Pract 2000
A successful palliative trajectory
GP involvement

GP’s

- Knowledge of patient prior to the palliative period
- Home visits
- Unplanned home visits
- Giving private phone number
- (Plan for out-of-hours)
- Contact to relatives

Community nurse involvement – successful trajectory

Community nurse’s
- Years as nurse
- Ekstra palliative education / training
- Knowledge of patient prior to the palliative period
- Contact with relatives
- Number of visits at home

**Question to bereaved relatives**

How, in your own words, was the entire period at home during which the deceased was dying compared with how you felt it should have been?

<table>
<thead>
<tr>
<th>Very well</th>
<th>Well</th>
<th>Fairly well</th>
<th>Bad</th>
<th>Very bad</th>
<th>Don’t know</th>
</tr>
</thead>
</table>

**Successful trajectory**

**Non-successful trajectory**
GP and CN involvement – successful trajectory

**Home death** was associated with a successful trajectory


**Neergaard MA, Olesen F, Vedsted P, Sokolowski I, Jensen AB, Sondergaard J**: *Associations between successful palliative cancer courses and community nurse involvement.* BMC Palliative care 2009;8:18
Key worker
Key worker

- Unclear definition
- Unclear agreement

**Neergaard MA**, Olesen F, Jensen AB, Sondergaard J: *Palliative care for cancer patients in a primary health care setting: Bereaved relatives' experience, a qualitative group interview study.* BMC Palliat Care. 2008

**Neergaard MA**, Olesen F, Jensen AB, Sondergaard J: *Shared care in basic level palliative home care - organizational and interpersonal challenges.* J Palliat Med 2010; 13(9)
Key worker

“The person who coordinates care, treatment and cooperation between all persons concerned in the disease trajectory”

Patient, Relative, GP and CN were asked:

“Who do you feel has been key worker since you (the patient) became ill?”
Conclusion – Key worker

- All participants most frequently saw themselves as having been the key worker!!
- Very low level of agreement!!
- Most frequently patients and relatives pointed to the GP as the ideal key worker

Symptom control
Symptom control

- Are GPs capable of delivering sufficient symptom control?
Symptom control – best practice

Questionnaire study
- 332 GPs from 208 different practices
- The City of Copenhagen

Gorlen T, Gorlen TF, Vass M, Neergaard MA. *GP confidence in being principally responsible for end-of-life care and use of fixed subcutaneous needle*. Submitted. 2011
How confident are you administrating medicine subcutaneously?

Proportion of doctors in %

- Very
- Somewhat
- Not very
- Not at all

Gorlen T, Gorlen TF, Vass M, Neergaard MA. *GP confidence in being principally responsible for end-of-life care and use of fixed subcutaneous needle*. Submitted. 2011
How confident are you with converting from orally to subcutaneously administered medicine?

Gorlen T, Gorlen TF, Vass M, Neergaard MA. GP confidence in being principally responsible for end-of-life care and use of fixed subcutaneous needle. Submitted. 2011
Conclusion – symptom control

- The study indicates that GPs need more education and support in symptom relief in terminal care

Gorlen T, Gorlen TF, Vass M, Neergaard MA. *GP confidence in being principally responsible for end-of-life care and use of fixed subcutaneous needle*. Submitted. 2011
Summary

- Most Danish cancer patients prefer to die at home
- Successful trajectory – dying at home
- Key worker concept is unclear
- GPs need education / support
Challenges doing palliative care research in primary care / population approach

- Defining a palliative care population
- Retrieval of population
- Registration of home care services
- …..
Thank you for your attention!

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