Swedish Register of Palliative Care – an update

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(no conflicts of interest)
What is the Swedish Register of Palliative Care – SRPC?

• Task given 2004 given by the Swedish association for Palliative Medicine in order to recognize Palliative Medicine as a speciality of its own also in Sweden

• Started retrospective with staff answering 30 questions when the patient had died

• Aim – everyone who dies – everywhere
  Purpose – to show that staff can recognize 80 % of all deaths before they are a fact
Where are SRPC now?

• 290 of 290 communities are reporting
• 21 of 21 counties are reporting
• Many of the private care givers are reporting
• Leveled out on 60 000 reports of 90 000 deaths
60 000 reported deaths per year equals

- 7 per hour
- 167 per day
- 5000 per month
60,000 reported deaths per year organized

- 5 people
- 1,200 clinics
- 5,000 care giver units
With a little help from our friends

- Swedish Association of Local Authorities and Regions – SALAR
- National Board of Health and Welfare - Socialstyrelsen
- The Swedish Council for Palliative Care – NRPV
- Palliative developing center, Lund
Life

Diagnose  Prolonging life care  End of life care  Follow up

LCP

Knowledge base
Guidelines
National Care Plan
SPRC 2017 -
Who will care for the dying?

- 2 main caregivers
  - County councils (21)
  - Communities (290)

- 90 000 deaths per year
  - max 75 000 to be expected = planned for

- > 400 000 staff to provide care
2 main path ways

• Healthy
• GP contact when sick
• Hospital contact
• Basal Home care
• Advanced Home care

• Last care giver 5 – 50 days

• Old – ageing
• Home care
• Nursery home
• GP
• Maby acute to hospital

• Last care giver 200 – 500 days
2 main path ways

- Healthy
- GP contact when sick
- Hospital contact 35 %
- Basal Home care 5 %
- Advanced Palliative care 10 %
- Last care giver 5 – 50 days

- Old – ageing
- Home care
- Nursery home 35 %
- GP
- Maby acute to hospital
- Last care giver 200 – 500 days
Results 2016
Results 2016

Specialised Palliative Care

Nursing homes and home care

Hospital
Increasing number of reports

Number of reports

- Nursery home
- Short stay
- Hospital
- Spec pall care/Hospice
- Spec pall Home Care
- Common pall Home care
- Other
Increasing results
Increasing number of scientific publications

2016
2012
Increasing number of systematic activities

• Pay for performance
  - Governmental level 2010 - 2014
  - County level 2008 – 2016...

• More hands
  - Governmental level 2015 –

• Improvement projects
  - SRPC
  - Register center level
  - County level
1,200 clinics in different settings

Reported deaths 2015

- Other
- Common Pall Home care
- Specialised Pall Home care
- Hospice
- Hospital
- Short stay
- Nursery home
<table>
<thead>
<tr>
<th>Täckningsgrad 2013 - 2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ökat &gt; 10 %</td>
</tr>
<tr>
<td>Inom + - 10 %</td>
</tr>
<tr>
<td>Minskat &gt; 10 %</td>
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<tr>
<td>Sjö</td>
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</tbody>
</table>
What should we do now?

• Financing Euro 100 000 – 1000 000 – 400 000

• Extra work filling questionnaires

• Need for education – staff turnover

• More improvement faster
Fish bone

Better Palliative Care
Fish bone

Better Palliative Care

Feedback
Feedback

• Yearly report – for free

• Fixed and/or dynamic reports on the internet

• Quarterly report on a clinic level – for a fee

• Warning systems

• Regional feedback
Andel dokumenterade medicinska beslut om vård i livets slutskede respektive dokumenterad läkarinformation (%)
Fish bone

Better Palliative Care

Feedback

New questions
New questions

• Staff under estimate patient problems/symptoms
  Next of kin over estimate patient problems/symptoms
  Next of kin questionnaire

• Learn more about the use of Methadone
  Questionnaire for Hospices

• Patient needs in the living patient
  Questionnaire focusing on information, daily life and coming up problems
Fish bone

- Medical record
- Feedback
- New questions
- Better Palliative Care

Better Palliative Care
• Different systems is not a problem – it is the structure we need to deal with

• Today we have terms but the result is documented as free text

• Plan to make a list of palliative terms combined with fixed results AND national/international computer friendly terms like SNOMED CT. First version before summer 2016

• Ask users to start configuring their medical records
Fish bone

Better Palliative Care

Data collection

New questions

Medical record

Feedback
Data collection

• Today web forms and official registries

• Development by SALAR of a ’webform asking medical record’ – system
  Needs a structured medical record
  A lot of mapping

• When data is structured – data could be pushed instead

• Just got a project for patient reported data with teach back options
Fish bone

- Sustainability
- Medical record
- Feedback
- Data collection
- New questions
- Better Palliative Care
Sustainability

• Swedish national registries are driven by enthusiasts
  Financing has been for one year at a time

• What started as professionals being interested in the result of their treatment is now used for leadership and sometimes for economic reasons.

• This has to be a natural part of care giving and improving results
Thank You for listening