Development of community palliative care in Denmark:

Barriers and Facilitators

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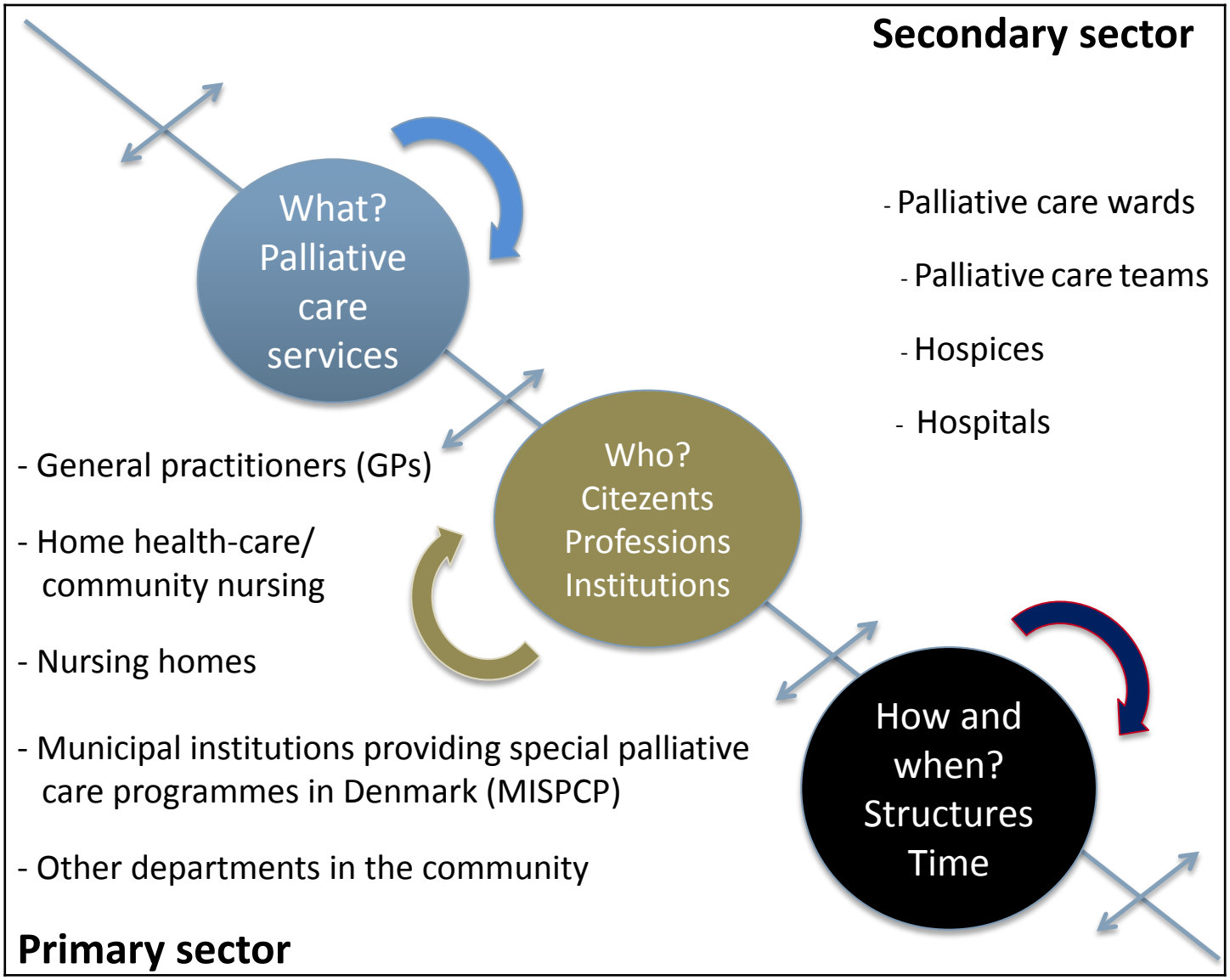
Secondary sector
What? Palliative care services
- Palliative care wards
- Palliative care teams
- Hospices
- Hospitals
Who? Citezents Professions Institutions
- General practitioners (GPs)
- Home health-care/ community nursing
- Nursing homes
- Municipal institutions providing special palliative care programmes in Denmark (MISPCP)
- Other departments in the community
How and when? Structures Time
Primary sector

2: Preferred place of care and death

- People with life threatning disease want to stay as long as possible in theirown home and if possible to die at home

However

- The wish to die at home decrease the further the person is in the disease trajectory and the more complex the symptomes become

Ref.: Neergaard, M. A., Bonde Jensen, A., Søndergaard, J., Sokolowski, I., Olesen, F., & Vedsted, P. (2011). Preference for place-of-death among terminally ill cancer patients in Denmark. *Scandinavian Journal of Caring Sciences*, *25*(4), 627-36.

2: Place of death in Denmark 2007-2011

- 47% in hospital
- 42% at home

Ref: Jarlbæk, L. (2015). *Dødssted og dødsårsager i Danmark 2007-2011.* København: PAVI, Videncenter for Rehabilitering og Palliation.

2: Challenges in palliative care services in communities (1)

- Most of the professionals have a short education
  - nursing assistant
  - Social- and health care workers

- About 36% of the care organisations have professions with palliative care postgraduate courses or further education

- More than 50% of the care organisations have a resource person in palliative care

However

- The ressource persons have great variation in formal contents of tasks and responsibility

Ref. Karstoft, Fisker Nielsen & Timm (2012). *Palliativ indsats i den kommunale pleje.* Palliativt Videncenter

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2: Challenges in palliative care services in communities (2)

- A need for proactive planning in palliative care

- The different professions have require
  - knowledge sharring
  - clear division of tasks
  - better communication
  - greater respect towards each others knowledge and competencies

  - GPs find palliative care complex and have a lack of knowledge about palliative care

- Management problems

Ref.:

Neergaard M.A, Olesen F., Bonde Jensen A. & Søndergaard J. (2010) Shared care in basic level palliative home care: organizational and interpersonal challenges. *Journal of Palliative Medicine*, 13(9), 1-7.

Brogaard T. (2011)Home is where the heart is: coordinating care and meeting needs in palliative home care: Ph.d. thesis. Aarhus: Aarhus University. Faculty of Health Sciences. Research Unit and Department for General Pratice.

Raunkiær M, Timm H (2010). Development of Palliative Care in Nursing Homes: evaluation

3: The project aims (2010-2013)

To strengthen and produce connections in community palliative care services to people with life-threatening diseases and their relatives in own home and nursing homes through 4 partial aims.

1. To develop and try out methods to develop competencies

2. To develop and try out structural and organisational frameworks

3. With starting point in the national recommendations and partial aim 1-2 to develop and test an interconnected intervention across community palliative care services and if possible in cooperation with the specialised palliative care institutions

4. To evaluate partial aim 1-3.

3: Design and participants

Design

- Action and intervention research

  1. Planning (meetings, survey, interviews and reviews)
  2. Implementation
  3. Assessement and communication

Participants

- Nyborg Municipality (two geographical areas)
- Research Unit of Practitioners, University of Southern Denmark
- PAVI

3: Interventions – practice / organisation

- Identification of citizents with the need of palliative care
- Devise a ‘Palliative Care Trajectory Plan’ (PCTP) to clarify the different professions area of responsibility and tasks
- Interdisciplinary home visits supported by guidelines and team meetings
- Systematic evaluation of the palliative care trajectory and the guidelines
- ‘Discovery form’ (DF) to nursing assistants/social- and health care workers to early discovery of persons who needed palliative care
- The quality of life form: EORTC-QLQ-C15-PAL to identify the need of palliative care

3: Interventioner
- competency development

- Teaching one afternoon for GPs and nurses together

- Course (3 + 2 days) for nursing ass/social and health care workers

3: The Gold Standards Framework (GSF) as a project frame

The goals of the GSF are to provide high-quality care for people in the final months of life by

- Ensuring patients are well symptom controlled
- Enabling patients to live and die well in their preferred place of care
- Encouraging security and support by better advance care planning involving the patient and their family
- Empowering cares through increased communication, listening and by addressing issues proactively
- Educating staff and developing increased competence and confidence

Ref.: Hansford P, Ceehan H. (2007). Gold Standards Framework: Improving community care. *End of Life Care, 1(3): 56-61.*

3: The three steps of GSF

1. Identify patients in need of palliative/ supportive care towards the end of life

2. Assess their needs, symptoms, preferences and any issues important to them

3. Plan-care, particularly with regard to looking ahead for problems that might arise

3: Step one - identification

GSF

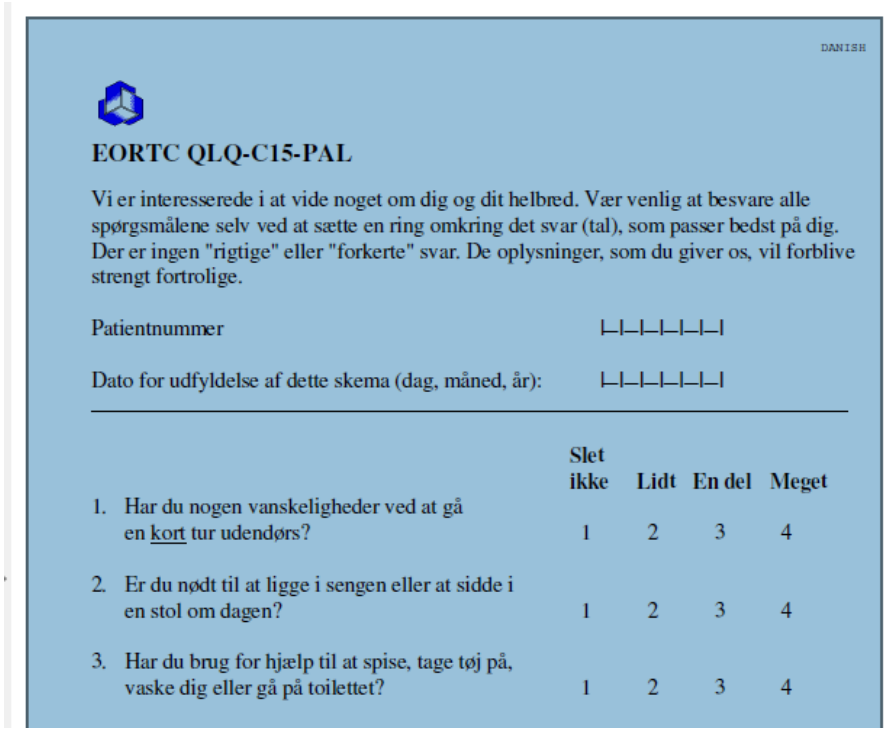
- The Surprise Question: “Would you be surprised if this patient were to die in the next few months, weeks, days?”
- General indicators of decline - deterioration, increasing need, or choice for no further active care
- Specific clinical indicators related to certain conditions.

Project

- DF to nursing assistants and social- and health care workers

3: Step two - assessment

- EORTC-QLQ-C15-PAL
- Conversations with the ill person and relatives
- DF to nursing assistants social- and health care workers



DANISH

EORTC QLQ-C15-PAL

Vi er interesserede i at vide noget om dig og dit helbred. Vær venlig at besvare alle spørgsmålene selv ved at sætte en ring omkring det svar (tal), som passer bedst på dig. Der er ingen "rigtige" eller "forkerte" svar. De oplysninger, som du giver os, vil forblive strengt fortrolige.

Patientnummer |_|_|_|_|_|_|

Dato for udfyldelse af dette skema (dag, måned, år): |_|_|_|_|_|_|

	Slet ikke	Lidt	En del	Meget
1. Har du nogen vanskeligheder ved at gå en kort tur udendørs?	1	2	3	4
2. Er du nødt til at ligge i sengen eller at sidde i en stol om dagen?	1	2	3	4
3. Har du brug for hjælp til at spise, tage tøj på, vaske dig eller gå på toilettet?	1	2	3	4

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3: Step three – plan-care

- Interdisciplinary home visits
- Team meetings

- PCTP

- EORTC-QLQ-C15-PAL
- PCTP
- DF
- Medicine

- Agreements/plans for after hours

- Everyday practice
- Competency development
- Evaluation of the palliative care trajectory

- Relatives / bereaved
- PCTP

- Other C'er
- Plans and agreements
- PCTP

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Forløbsbeskrivelse og tværfaglige indsatsområder i palliative forløb

HJÆLPERE/ASSISTENTER	Palliative faser	SYGEPLEJERSKER	Palliative faser	PRAKTISERENDE LÆGER
Tidlig opsporing • Opsporingsskema Evt. deltagelse i tværfaglige hjemmebesøg • Guide Personlig pleje Observationer Tilbagemelding til sygeplejerske Evaluering af palliative forløb • Guide	1 2 3 DØD	**Koordination af forløb** Tværfaglige hjemmebesøg med praktiserende læge mhp. plan/aftaler • Guide • EORTC-QLQ-C15-PALL Overvej: • Præst • Vågekone • Aflastningsplads • Fys., ergo., socialrådgiver Evaluering af palliative forløb • Guide Kontakt til efterladte ca. 8 dage – 30 dage efter dødsfald mhp. samtale	1 2 3 DØD	**Tovholder på medicinsk behandling** Tværfaglige hjemmebesøg med sygeplejerske mhp. plan/aftaler • Guide • EORTC-QLQ-C15-PAL Overvej: • Forslag til soc.med. sagsbehand. (LÆ 165) • Terminalansøgning • Grøn recept • Tryghedskasse • Palliativt Team andre professionelle • Åben indlæggelse • Øget tilgængelighed (udveksling af tlf.nr.) Evt. evaluering af palliative forløb • Guide

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4: Project evaluation

- Five focus group interviews with 21 professionals
- Survey of the competency development - 88 nursing assistant / social- and health care worker
- Survey with 13 bereaved

4: Project evaluation - facilitators (1)

GSF

- Increased the professional overview
- Contributed to early palliative care
- Increased palliative care to people with non-cancer diseases and very modest people

The local developed intervention tools

- PCTP had increased the professional confidence because of
  - structured palliativ care trajectory
  - clarified division of responsibilities between nurses and GPs
- The guidelines for the interdisciplinary home visits

4: Project evaluation - facilitators (2)

EORTC-QLQ-C15-PAL contributed to

- better dialog with the ill person
- opening up for talks about palliative care
- allowing the ill person to speak about problems
- brinning the ill persons often surprising own judgement to the nurses
- the nurses experiencing to have an overview
- the qustions being easy to remember and use in other connections

4: Project evaluation- barrierers (1)

- Reorganisations and cost savings in the municipality
- Difficulties in chaging everyday routines in profesional practice
- Lack of continuous reflection processes about the interventions
- The IT systems were insufficient
- Many and to comprehensive interventions at the same time
- Competing projects

4: Project evaluation- barrierers (2)

- Lack of concrete management endorsement at different levels
- Lack of commitment among some of the professionals to work with the interventions
- The fact that GPs are self-employed and organized to the Danish regions, wheras nursing homes etc are a part of the municipality made differences in project commitments

Thank you for listning

Selected references

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