

## Press release

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### Basic information

Name: Camilla Askov Mousing

Email: [cm@ph.au.dk](mailto:cm@ph.au.dk) Phone: +45 87552166

Department of: Public Health

Main supervisor: Kirsten Lomborg

Title of dissertation: Improving the palliative care of people with chronic obstructive pulmonary disease in home care: a participatory action research project

Date for defence: 22. June 2017 at (time of day): 14.00 Place: Merete Barker Auditoriet

Press release (Danish)

Forbedring af den palliative indsats til mennesker med kronisk obstruktiv lungesygdom i hjemmeplejen: et aktionsforskningsprojekt

Et nyt ph.d.-projekt fra Aarhus Universitet, Health, har undersøgt palliative behov hos patienter med kronisk obstruktiv lungesygdom (KOL) i hjemmeplejen og sundhedspersonalets muligheder for imødekomme disse behov. På baggrund af patienternes og sundhedspersonalets (sygeplejersker, social- og sundhedsassistenter og social- og sundhedshjælpere) oplevelser med lindrende indsatser til patienter med KOL i hjemmeplejen, blev der udviklet et undervisningsprogram for at øge sundhedspersonalets evner til at se patienternes behov og igangsætte og evaluere en lindrende indsats. Undervisningsprogrammet blev udviklet i et samarbejde mellem forskere, sundhedspersonale og ledere i hjemmeplejen. Det blev afprøvet i hjemmeplejen i en større dansk kommune og efterfølgende evalueret.

Afhandlingen indeholder tre videnskabelige artikler. Centrale fund fra forskningsprojektet var, at patienter med KOL oplevede angst og åndenød i hverdagen og bekymrede sig for sygdommens indflydelse på fremtiden og døden. Patienterne gik ofte alene med bekymringerne og delte dem hverken med familie eller sundhedspersonalet. Patienterne ønskede at modtage hjælp i hjemmet af kendt personale og ønskede, at sundhedspersonerne indledte samtaler om KOL-relaterede bekymringer. Sundhedspersonalet oplevede før deltagelsen i undervisningsprogrammet, at de manglede viden om KOL og palliation, og de var ikke opmærksomme på patienter med KOL som målgruppe for lindrende indsatser. Sundhedspersonalet var bange for at ødelægge patienternes håb for fremtiden ved at tage hul på samtaler om palliative behov. Efter deltagelse i undervisningsprogrammet oplevede sundhedspersonalet at have fået større fokus på palliative behov hos patienter med KOL. De oplevede at have større tiltro til egne evner i forhold til at identificere palliative behov og iværksætte lindrende indsatser. De oplevede også at have tilegnet sig viden og værktøjer til at håndtere akutte KOL-symptomer som angst og åndenød sammen med patienten. Sundhedspersonalet oplevede, at deres frygt for at ødelægge patienternes håb for fremtiden ved at invitere til samtale om palliation var mindsket. Projektet satte desuden fokus på organisatoriske udfordringer i hjemmeplejen. Disse udfordringer handlede om struktur, tid og planlægning. Det udviklede undervisningsprogram har ifølge deltagerne understøttet projektets formål om at øge sundhedspersonalets evne til at identificere palliative behov og igangsætte og evaluere palliative indsatser i hjemmeplejen. Projektet er gennemført af Camilla Askov Mousing, der forsvare sin afhandling d. 22/6-2017.

Forsvaret af ph.d.-projektet er offentligt og finder sted den 22/6 kl. 14.00 i Merete Barker Auditoriet, Aarhus Universitet, Bartholins Allé 3, Aarhus. Titlen på projektet er "Improving the palliative care of people with chronic obstructive pulmonary disease in home care: a participatory action research project". Yderligere oplysninger: Ph.d.-studerende Camilla Askov Mousing, e-mail: [cm@ph.au.dk](mailto:cm@ph.au.dk), tlf. +45 87552166.

Bedømmelsesudvalg: Geralyn Hynes, Associate Professor, School of Nursing and Midwifery, Trinity College Dublin, Ireland. Kristin Bjornsdottir, Professor, Faculty of Nursing, University of Iceland, Iceland. Marianne Lisby, Associate Professor, Emergency Department, Aarhus University Hospital and Research Centre of Emergency Medicine, Denmark.

Press release (English)

Improving the palliative care of people with chronic obstructive pulmonary disease in home care

A new PhD project from Aarhus University, Health, has investigated palliative care needs in patients with chronic obstructive pulmonary disease (COPD) in a home care context, as well as professional caregivers' ability to meet these needs. Based on patients' and professional caregivers' experiences of palliative care in home care, an educational programme was developed to increase professional caregivers' ability to identify palliative care needs and initiate and evaluate palliative care. The programme was developed in collaboration between researchers and stakeholders (professional caregivers and leaders in home care). The educational programme was implemented in home care in a Danish municipality and subsequently evaluated.

The PhD thesis contains three scientific articles. The central findings from the research project were that patients with COPD were experiencing anxiety and dyspnea in everyday life and worried about the impact of COPD on future life and death. Patients often hid their concerns and did not share them with family or professional caregivers. The patients wished for staff continuity and wished for the professional caregivers to initiate conversations about COPD-related concerns. Prior to participation in the educational programme, professional caregivers experienced a lack of knowledge about COPD and palliation and they were not aware of patients with COPD as a patient group with possible palliative care needs. The professional caregivers were afraid of destroying the patients' hope for the future by initiating palliative care conversations. After participating in the educational programme, the professional caregivers experienced to have gained a greater focus on palliative care needs in patients with COPD. They experienced greater confidence in their own ability to identify palliative needs and initiate palliative care. Also professionals experienced having acquired knowledge and tools to handle acute COPD symptoms such as anxiety and breathlessness. The professional caregivers experienced to be less afraid of destroying the patients' hope for the future by initiating conversations about palliation. The research project has also focused on organizational challenges in home care. These challenges concerned structure, time and planning.

According to the participants, the developed educational programme has supported the project's aim about increasing professional caregivers' ability to identify palliative care needs and initiate and evaluate palliative care interventions in home care. The project was carried out by Camilla Askov Mousing, who is defending her dissertation on 22/6-2017.

The defence is public and takes place on 22/6 at 14.00 in Merete Barker Auditorium, Aarhus University, Bartholins Allé 3, Aarhus. The title of the project is "Improving the palliative care of people with chronic obstructive pulmonary disease in home care: a participatory action research project". For more information, please contact PhD student Camilla Askov Mousing, email: [cm@ph.au.dk](mailto:cm@ph.au.dk), Phone +45 8755 2166.

Assessment committee: Geralyn Hynes, Associate Professor, School of Nursing and Midwifery, Trinity College Dublin, Ireland. Kristin Bjornsdottir, Professor, University of Iceland, Faculty of Nursing, Iceland. Marianne Lisby (Chairman), Associate Professor, Emergency Department, Aarhus University Hospital and Research Centre of Emergency Medicine, Denmark.

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