



Ethical aspects of palliative care project



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Background

▶ **Background:**

- ▶ Greenland has a population of approximately 56,000 inhabitants and the majority lives (over 90%) in West Greenland. The number of patients with cancer is increasing in Greenland. The incidence in 2011 was 195 with a rate of 344.4 per 100,000 inhabitants, compared with 320.6 in 2010. Currently about 112 Greenlanders die annually from cancer.
- ▶ The population's life expectancy is rising, but is still relatively low (68 years for men and 73 years for women). Since 1993 population surveys have shown that the main health problems are musculoskeletal disorders, diabetes, hypertension and cancer.
- ▶ The most common cancers in the period 1980-2009 are lung cancer, breast cancer, cervical cancer, colon, esophagus, pancreas, stomach, nose / throat, rectum and ovarium. Of 370 cancer-related deaths in 2008-2010 10% died at home, 12% in nursing homes and the rest in hospitals. A review of patient charts indicated that Greenlanders are diagnosed with cancer late in the disease trajectory, and there is a lack of continuous monitoring of mortality and survival.
- ▶ Palliative care for patients with cancer are carried out in small village nursing stations, health centers in minor cities, regional hospitals in the cities, the nationwide Queen Ingrid Hospital in Nuuk and if not sufficient, it may be necessary to seek for assistance at Rigshospitalet or other hospitals in Denmark. There is neither specialized palliative care nor day-and-night-care in Greenland.
- ▶ Therefore, there is a urgent need to identify and describe the patients' and their relative's need as the basis for developing palliative care. In particular, the focus should be on how more palliative cancer patients may be able to spend more time in or near their own home with the family.



Ph.d.project

- ▶ The study is divided in to three studies:
- ▶ Symptomatology and health related quality of life of Greenlandic patients with advanced cancer
- ▶ Satisfaction with care among relatives to patients with advanced cancer
- ▶ Health professionals and palliative care services in the Greenlandic health system.



Methods and design:

- ▶ Study I:
 - ▶ Symptomatology and health related quality of life of Greenlandic patients with advanced cancer:
 - ▶ Populationbased cross sectional
 - ▶ Prospective study: development of symptoms and problems
 - ▶ The Greenlandic Version of EORTC-QLQ-C30 is used
 - ▶ Monthly interviews were conducted using the questionnaire EORTC-QLQ-C30. Additionally, patients are asked an open question about what takes up most of their lives right now.
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Relatives perspectives on treatment and care

- ▶ Study 2:
- ▶ Patient with advanced cancer are asked to point out a close relative who will then be interviewed. Satisfaction with care is being explored by conducting structured interviews using FAMCARE questionnaire and an open question about what takes up most of their lives right now.
- ▶ Analysis of data is ongoing



Health professionals in the Greenlandic health care system

- ▶ Study 3:
- ▶ In the third study we have conducted qualitative interviews with health professionals working in the Greenlandic health system.
- ▶ There will be conducted focus group interviews with health professionals working in the Greenlandic health with the aim to identify existing palliative services and to get an overview of barriers and opportunities to develop palliative care.
- ▶ Analysis of data: transcriptions have been done



Results (briefly) study 1

- ▶ n= 58 (population based cross sectional study) n= 49 (prospective study)
- ▶ Mean age 59, men (n=37)= 62, women (n=21) 56
- ▶ Single living = 39%
- ▶ Lung cancer= 45% (gastrointestinal 21%, breast cancer 14%, andet 20%)
- ▶ Low income 100.000 kr annually: 51%
- ▶ Resident in Nuuk= 24%



Results study 2

- ▶ 29 caregivers/relatives participated and filled in the questionnaire, some cannot fully answer questions due to no contact to health care system
- ▶ Frequent problems are lack of information
- ▶ No opportunity to be with the sick during treatment
- ▶ They have a big wish of being with their sick one
- ▶ Lack of opportunity of getting in contact of health professionals with specific problems regarding medicine, and other symptoms



Health professionals

- ▶ 3 individual interviews with professionals in three settlements
- ▶ Focusgroup interviews with staff from Det Grønlandske Patienthjem
- ▶ Group interview with to doctors and leaders in DIH

Briefly: Professionals experience a growing need to develop the care for patients with advanced cancer and there are major geographical and infrastructural challenges. Solutions regarding increased palliative care must be creative.



Ethical challenges

- ▶ Many patients and relatives are underinformed about prognosis- challenging for research
- ▶ It is an observational study- and many needs of both patients and relatives
- ▶ Clinical trial ENABLE: Three themes related to trial participation: helping future patients and contributing to science, gaining insight through completion of questionnaires, and trial/intervention aspects to improve. (2013)



Thank you

