

**Results:** Despite a small sample, the study reveals great diversity in both patient and relative experiences of ACP.

Some felt 'relieved,' 'more secure' and more in control, because the patient's preferences had become known. For a few, ACP had led to open communication rather than 'beating around the bush', to spending more quality time together, and to feeling 'more prepared' for death. However, others perceived ACP as irrelevant. Some stated that the patient's wishes had not been met regardless of ACP. Others felt that EOL questions cannot be realistically considered until 'you're right in the middle of it' since so many factors are involved. In one case, participating in ACP had led to a patient-relative conflict, resulting in illness and EOL issues being 'tucked away'.

**Conclusion:** This study shows that ACP carries the risk of being inconsequential or even damaging to communication. The study thereby challenges previous research which mainly emphasises ACP as a valuable tool to optimising EOL care.

This study stresses the importance of awareness of the highly individual nature of preferences and needs of patients and relatives regarding information, involvement, and communication about EOL care.

The study is funded by the Danish Cancer Society.

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### Differences in Preferred Place of Care and Place of Death Between Cancer and Non-cancer Patients in Palliative Trajectories

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**Background:** Congruence between preferred and actual place of care (POC) and place of death (POD) is considered an essential component in end-of-life care. Existing literature on this subject is limited and based mainly on cancer patients. As a result, there may be a tendency to apply knowledge from cancer to non-cancer settings. Hence, knowledge is needed to clarify if patients with non-cancer diagnoses have different preferences than cancer patients regarding POC/POD.

**Aim:** To investigate possible differences in preferred POC and POD between cancer and non-cancer patients in palliative care trajectories.

**Methods:** To identify possible differences in preferred POC/POD, three groups of patients are included in this study. Patients with heart failure, lung disease or cancer respectively participate in a prospective randomised controlled trial testing feasibility and possible advantages of *Advance Care Planning* (ACP) in a Danish context. Participating patients are asked about preferred POC/POD in the baseline questionnaire of the ACP study. Eligible patients with an estimated lifetime of 6-12 months are included. The first 40 consecutive patients from each of the three diagnostic groups will be included in the present study. The inclusion of patients began November 2013 and ends May 2015. Until now 78 patients have been included in all. Relevant regression models will be used to compare the preferences, allowing adjustment for age and gender. The project is funded by The Danish Cancer Society and Trykfondens.

**Results:** Data of patients' preferences regarding preferred POC/POD will be presented.

**Conclusion:** Knowledge of preferences regarding POC and POD among patients with various diagnoses and at an individual level is imperative in improving quality of end-of-life care. This study adds awareness to the possibility that preferences regarding POC and POD may differ between patients with different diagnoses and thus may help target future research appropriately.

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### Communication with Cancer Patients

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**Background:** Effective patient-physician communication is at the core of health care, especially for cancer patients. The importance of education of communication skills to medical students have been recently acknowledged in medical universities in Iran.

**Aims:** To identify what cancer patients expect from communication with their oncologists.

**Methods:** Non-structured and experimental medical interview with more than 2000 patients with advanced staged of cancer who were referred to palliative care clinic from 2011 to 2014.

**Results:** The following list of recommendation for physicians has been generated based on the most frequent points mentioned by the patients.

1-In presence of patients, it is preferred to directly address them rather than their relatives  
2-Let the patients talk about themselves; physical problems, emotional feelings, spiritual suffering and even economic problems. The physicians cannot solve all these problems but by being heard makes the patients comfortable.

3-If the patients need and want to know about their diseases the physician should completely explain for them.

4-The patient should be examined in each visit even if the physician thinks that it is not required.

5-Although the whole truth about the disease or its outcome might not be revealed to the patients, any lie should be avoided.

6-The physician shouldn't be indifferent while telling bad news to the patient.

7-The physician should avoid telling something to the patient which makes him/her feel remorse.

8-The physician should avoid giving the patient a define time limit for their living.

9-The patient should be allowed to try their preferred unconventional treatment even if the physician found them unhelpful.

10-Use of humor in communication with the patients is recommended.

**Conclusion:** Education of communication skills should be part of curriculum of medical students and residents of all specialties.

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### Sharing the Diagnosis of Dementia: Breaking Bad News to People with Intellectual Disabilities

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**Background:** Following previous research findings that existing models for breaking bad news to patients who have a life-limiting illness are inadequate in meeting the needs of people with intellectual disabilities (ID), a 2 year study into breaking bad news to this group of patients/relatives resulted in the development of a new model for breaking bad news to people with ID, which was presented at the EAPC Conference 2011 in Lisbon. The model is based on the finding that bad news situations are usually complex and are made up of lots of different chunks of knowledge and information; the acquisition of these chunks is a non-linear process that can be unpredictable. Building someone's foundation of knowledge and understanding is central to the model. It has been used successfully in practice; however, it is unclear how this can be applied to people with ID and dementia. UK and European dementia strategies specify that everyone is entitled that everyone is entitled to know of their diagnosis.

**Aim:** To explore whether the new model for breaking bad news can be used effectively in sharing a diagnosis of dementia with people with ID.

**Methods:** The model was applied to people with dementia and ID as follows:

(1) the literature on dementia and breaking bad news was analysed;

(2) theoretical assumptions were made based on the model itself;

(3) the model was applied in real-life situations.

**Results:** Through a case study, we will present how the model for breaking bad news was used. A man with ID had not been told about his dementia diagnosis, nor about his mother's terminal cancer. The model was helpful to both the client and his support staff in helping him understand and cope with his changing situation.

**Conclusion:** This initial exploration of the use of the model has promising results, but a study is now underway to investigate further how people with ID and dementia can be best supported in their need for understanding.

## Development and organisation of services

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### CASA Study: Care and Support Access - Implementation of a Palliative Approach for HIV+ Young Men who Have Sex with Men to Improve Engagement and Outcomes - Preliminary Results

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**Background:** Early implementation of a palliative approach (EIPA) can improve chronic disease management. We target a subset of people living with human immunodeficiency virus (PLWH) to demonstrate how EIPA can be introduced for non-palliative specialists. HIV positive young men who have sex with men (YMSM) remain at risk for poor outcomes facing myriad impediments to achieving disease control.

**Methods:** EIPA, facilitated by an educational intervention combining iterative teaching and on-site coaching, patient representatives and emphasis on self-care for staff used to introduce key elements of PC into the management of HIV disease. The interdisciplinary team guided by patient-family needs, focuses upon goal-setting, symptom management, and communications skills. We intend to:

- 1) determine the impact of EIPA to improve patient-centered care;
- 2) describe the impact of EIPA upon YMSM relative to decreasing viral suppression, impact on mental health and quality of life (QOL); and
- 3) describe the impact of EIPA upon staff with regard to reducing stress of providing care. Mixed methods and a quasi-experimental design are used to compare outcomes in a longitudinal sample of 204 YMSM from two outpatient clinics in one urban U.S. city.

**Results:** In the era of HIV disease control preliminary data shows a co-morbid population. Of 57 YMSM currently enrolled 66% are under 30. The majority self-identify as African-American (75%), Hispanic (11%), and mixed (11%). Thirty-two percent have a high school education; 17% have less. Thirty-two percent are employed; 16% are disabled. Despite the young age, 30% have been incarcerated. 74% report skipping medication, a third have missed at least half of their scheduled appointments. Drug use/abuse history: marijuana (80%), cocaine (26%), amphetamines (11%), alcohol dependence (23%).

**Conclusions:** EIPA is being tested to improve outcomes in patients known to be non-adherent. Staff are evaluated for stress relative to care delivery.