



**FOLKETINGET
STATSREVISORERNE**



**FOLKETINGET
RIGSREVISIONEN**

**August 2020
– 18/2019**

**Extract from Rigsrevisionen's report
submitted to the Public Accounts Committee**

Access to specialist palliative care

1. Introduction and conclusion

1.1. Purpose and conclusion

1. This report concerns access to specialist palliative care in the Danish healthcare system. The purpose of palliative care is to ensure early identification and relief of pain and other problems associated with life-threatening disease, for the patients as well as for their families. The patients' symptoms and problems can be of physical, psychological, social and spiritual nature.

2. In 2018, approx. 39,500 people died of a life-threatening disease in Denmark. The Ministry of Health assumes that many of the patients that die of a life-threatening disease like, for instance, cancer, heart or lung disease, need palliative care. Palliative care is multidisciplinary and is provided as either general palliative care or specialist palliative care, depending on the patients' needs. The majority of patients receive general palliative care, provided in the municipalities and in the regions. Specialist palliative care is provided to patients with complex palliative needs in the following settings: specialist units in regional hospitals or independent hospices working under contract with the regions. Approx. 11,000 patients were referred to specialist palliative care in 2019.

For the past 20 years, regional as well as national initiatives have been launched to develop and improve palliative care. National initiatives are primarily rooted in the national cancer plans.

3. Rigsrevisionen initiated the study in October 2019, because data from the national palliative database showed that across the country ensuring the patients' access to specialist palliative care is a challenge.

4. The purpose of the study is to assess whether the regions ensure the patients' access to specialist palliative care, when they need it. The patients' access should be needs based and not disease based. The study covers the pathway from identification of the patient's need for palliative care to the admittance of the patient in a specialist palliative care unit in a hospital or a hospice.

The study is based on the underlying assumption that in order to ensure optimal relief of the individual patient's symptoms, palliative care should be integrated earlier in treatment pathways through identification of the patients' needs. To limit the number of rejected referrals to a minimum, the identification of the patient's needs must clarify which criteria the patient should meet to be successfully referred to specialist palliative care. Efforts should be made to ensure that referred patients are admitted to a specialist unit in a hospital or hospice without undue delay.

Palliation

Palliation is the medical term for relief (of pain or other symptoms).

General palliative care

General palliative care is provided to people with specific and well-defined palliative needs. It is provided as an integral part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team. General palliative care is provided in most hospital departments, municipal home care and home nursing care services), by GPs and other practitioners (e.g. psychologists and physiotherapists).

Specialist palliative care

Specialist palliative care is provided

- in palliative departments with units admitting patients with palliative needs;
- by multidisciplinary palliative teams in an outpatient setting or at home;
- in hospices where terminal patients can be admitted for end of life care.

The national cancer plans include various initiatives and investments and aim to improve the treatment of cancer in Denmark.



Main conclusion

The regions have not adequately ensured that patients, when required, have access to specialist palliative care. The patients' symptoms may therefore not be effectively relieved towards the end of their life, which diminishes the quality of their life and places an unnecessary burden on their relatives.

Rejection

Patients, whose referrals are rejected, are not offered specialist palliative care. Referrals are rejected, for instance, if the patients do not meet the criteria of referral.

Patients with life-threatening diseases in need of palliative care are not identified systematically, and patients risk not being referred to specialist palliative care, when required. The study found that the hospital departments, that are meant to identify and refer patients to specialist palliative care, are not systematically using tools to ensure that the patients' need for palliative care is identified early and regularly in the course of their disease and regularly thereafter. The Danish Health Authority's recommendations are based on the assumption that patients with cancer and patients with other diseases have the same need for palliative care in the terminal phase of their disease. In 2018, 640 patients out of 1,000 that died of cancer had been referred to specialist palliative care. Out of 1,000 patients that died of other diseases, 34 had been referred. The regions are not monitoring whether the referral criteria are clear or whether the appropriate patients are referred by the hospital departments. Twelve per cent of all referrals of cancer patients to specialist palliative care are rejected, against a rejection rate of 24% for patients with other diseases than cancer. Across the regions, the difference in number of patients that are referred and rejected referrals is considerable.

Many patients are not admitted in time before they die or before it is too late for them to benefit from palliative care, and many of the patients that are admitted in time wait for too long for specialist palliative care. The regions have set a national target of 80% for the admittance of cancer patients before they die or no longer are in a condition where they will benefit from palliative care. This target was achieved in the period 2016-2019, during which 81-82% of all cancer patients were admitted. However, only 69-73% of all patients with other diseases than cancer were admitted over the same period. The study shows that the target of 90% set for admittance of patients within 10 days was not achieved during this period. 73-75% of all cancer patients were admitted within the 10-day deadline in 2016-2019. 73-75% of all patients with other diseases than cancer were admitted within the deadline in the period 2016-2018, but the percentage dropped to 68% in 2019. It is Rigsrevisionen's assessment that achievement of the target set for admittance could be adversely affected in the regions, whose practice is more in line with the recommendations on referral of patients to specialist palliative care. There are considerable differences across the regions regarding the number of patients that are admitted before they die or no longer will benefit from palliative care and the number of patients that are admitted within 10 days.

The study found that access to specialist palliative care had not improved significantly in the period 2016-2019; the knowledge of individual patient's and patient groups' need for palliative care is insufficient, patient referrals are rejected, and many patients are offered palliative care too late in the course of their disease.

The results of the study indicate that cancer patients and patients with other diseases than cancer do not have the same access to specialist palliative care. The indications are based on the Danish Health Authority's assumption that all patients with a life-threatening disease have the same need for palliative care. However, knowledge on whether patients with cancer and patients with other diseases than cancer have the same need for specialist palliative care is not available.

It is Rigsrevisionens opinion that as a first step towards ensuring that access to specialist palliative care to a higher degree is based on the patients' needs, the Ministry of Health and the regions should address the inadequate identification of patients in need of palliative care. This could be done, for instance, within the framework of the Task Force on Patient Pathways for Cancer and Heart Disease.

Task Force on Patient Pathways for Cancer and Heart Disease

The purpose of the task force is to ensure optimal care pathways for cancer and heart disease patients. The task force has focus on the pathway from the first suspicion of cancer or heart disease to diagnosis, treatment (curative and life-prolonging), follow-up, rehabilitation and long-term side effects.

The task force is made up of representatives from *Danske regioner* (interest organisation for the five regions in Denmark), the five regions, *KL* (interest organisation for the 98 Danish municipalities), the Ministry of Health and the Danish Health Authority (chair).

The Ministry of Health and the regions follow up on the implementation of recommendations concerning palliative care in the task force.