



Collaboration in palliative care cancer research



Understanding palliative care

Julie Ling, CEO of the European Association for Palliative Care sheds light on palliative care and how it puts the patient first in terms of treatment...

According to the World Health Organization (WHO), the main aim of palliative care is to enhance quality of life for people with life-limiting conditions where cure is not possible, helping them to live well until they die. Palliative care is an active approach that affirms life and views death as a normal process. Priding itself on treating people with dignity, compassion and respect, palliative care neither hastens nor postpones death.

There is a common misperception that people can only receive palliative care at end of life when other treatments are no longer possible, but in reality palliative care can be provided for people of any age and at any stage of their

illness; when introduced early, palliative care aims to positively influence the course of an illness. Sometimes by providing palliative care at an early stage in a person's illness, for example, while using treatments such as radiotherapy or chemotherapy, symptoms and complications can be managed more effectively.

WHO stress the importance of the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems which some people with life-limiting conditions experience. Usually based on research evidence, the majority of symptoms can be treated effectively which can result in improved quality of life.



Importantly, palliative care considers all aspects of caring for a person including physical, social, psychological and spiritual care. This holistic view to palliative care is most effective when provided by a team approach; this includes access to a range of healthcare professionals with varying and complimentary skills.

Palliative care sees the patient as an integral part of their family and community; therefore, care is also extended to support families. This care aims to help them with their family member's illness and following death, provides bereavement support to help cope with their loss and grief. Palliative care can and should be provided in any location including hospital,

hospice and home and can also be provided in any other location where the person is receiving treatment or care. Palliative care is not the exclusive domain of those working in the specialty, and is the responsibility of the whole healthcare team. The planning and provision of care should be tailored specifically to meet the individual needs of the person and their family.

As an indication of the growth and development of palliative care, throughout Europe, the European Association for Palliative Care has 55 member associations from 31 countries. Palliative care services are at varying stages of development across Europe and the rest of the world. Recent developments including the reorientation of palliative care as a public health imperative by WHO, will help to ensure that some of the barriers to providing palliative care (e.g. limited access to appropriate pain medication) are removed. Such initiatives also aim to ensure that the specialty is developed and strengthened thus enabling all those who require palliative care to access appropriate services, regardless of their geographical location or disease diagnosis.

Evidence suggests that access to palliative care improves quality of life, to make decisions regarding their dying and enables people with life-limiting conditions to live as well as possible until they die.

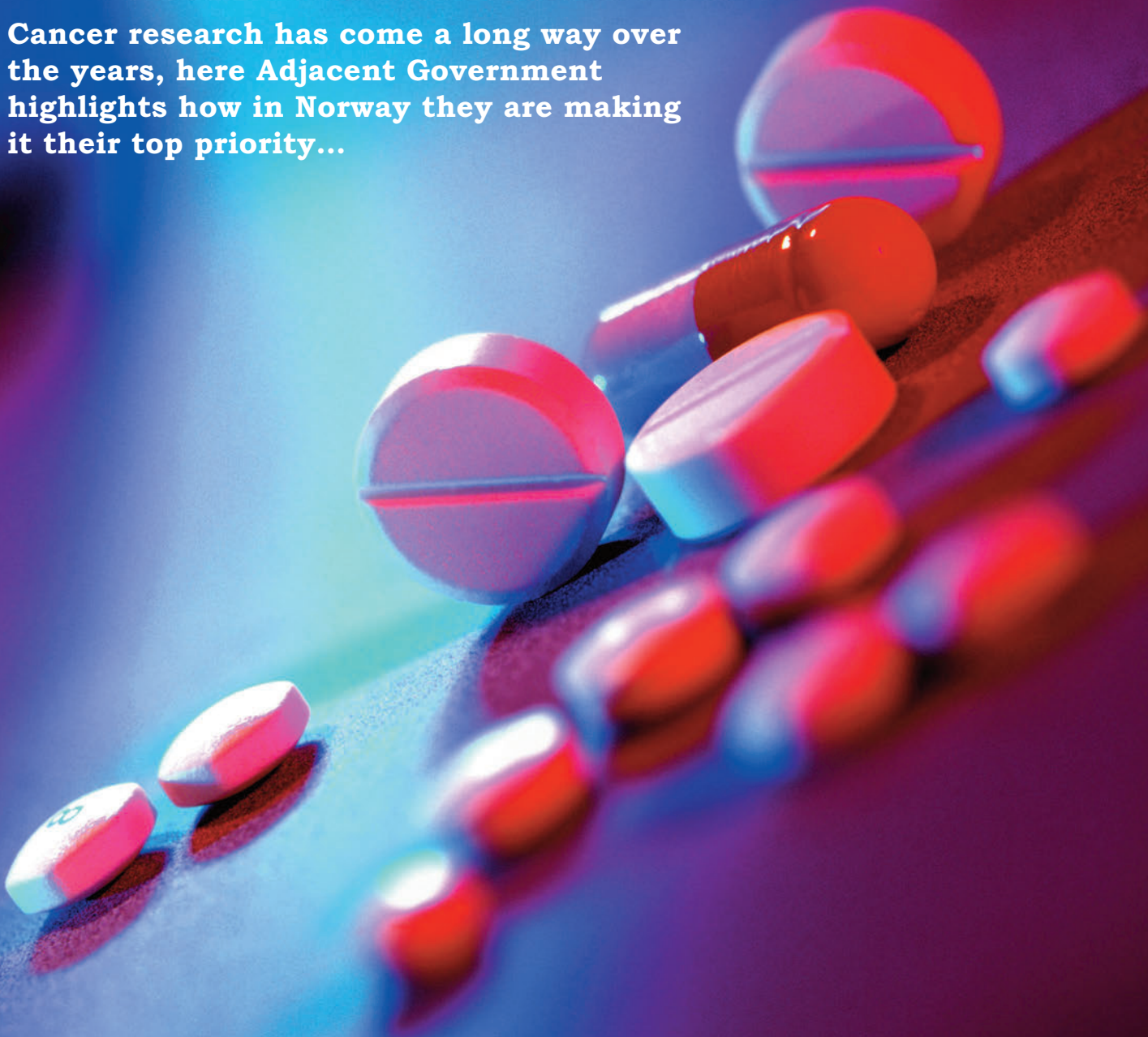


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Cancer research in Norway

Cancer research has come a long way over the years, here Adjacent Government highlights how in Norway they are making it their top priority...



Over the last 10 years in Norway life sciences and medical research has come a long way, with researchers being able to tackle some of the major healthcare challenges.

In 2012, The Norwegian Cancer Society reported that there were 30,099 new cases of cancer, with prostate, breast, lung and colon being the most common burdens; these accounted for 45% of total cases. Almost half of cancers in Norway are diagnosed in people aged 70 or over, and roughly 2 out of 3 patients are alive 5 years after being diagnosed.

The Research Council of Norway has funded cancer research through a variety of schemes. Introducing the Strategic Initiative on Cancer Research in 2000, the Council understands that research is one of the primary tools to combat cancer, aiming for improved prevention, diagnosis and treatment.

Through this initiative the Research Council aims to focus on clinical research, with an aim of giving patients the opportunity to live longer and healthy lives cancer free.

In 2013 the Norwegian government launched their National Cancer Strategy 2013-2017, 'Together – against cancer'. Through the strategy the government and the Ministry of Health and Care Services aim to establish a higher level of cancer care in the country.

At the time of launching the Strategy, Former Minister for Health and Care Services, Jonas Gahr Støre said: "Cancer challenges us all in various ways. Even though treatment has improved and an increasing number of patients survive cancer, the number of individuals affected is also increasing.

"Cancer is not one, but many different diseases. One of the greatest challenges faced

by cancer care is therefore the development of more targeted and personalised cancer treatment, adapted to the specific type of cancer and the individual's qualities, opportunities and needs."

In order to develop more targeted treatments, research must play a key role. In October this year, Director General for the Research Council of Norway Arvid Hallen said: "In the national budget proposal for 2016, the government is giving research and innovation a more important role than ever in the restructuring of the Norwegian economy."

"Given the current economic situation, it is both correct and necessary to strengthen industry-orientated research, long-term basic research and mobilisation for participation in EU research programmes, as the government is now doing."

Funding from the Research Council is integral to support and boost areas such as cancer research. They reported that the budget proposal recommends an increase of NOK 25 million for the support scheme for laboratories and equipment.

"The investment in world-leading research groups will make it possible to bring to fruition top-quality work led by our best researchers. This will enable Norway to cultivate a greater number of internationally leading research groups that can distinguish themselves on the research front," said Mr Hallen.

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Collaboration in palliative care cancer research

The Norwegian experience illustrates the importance of suitable organisation and national and international collaboration in developing and strengthening palliative care research

Mainland Norway is more than one and a half times the size of Great Britain, but has only 5.2 million inhabitants. The country stretches far north, and large areas have a scattered, sparse population. Even though equal access to health care services is a challenge, Norway has a comprehensive, well-functioning public health care system with a regional structure.

Cancer palliative care

Norway has more than 30,000 new cancer cases per year, and the number is rising. Advances in cancer care have led to more patients being cured or living longer with their disease. Still, the country has close to 11,000 cancer deaths per year.

With the country's first national cancer plan in 1997, Norway had its first national strategy for palliative care. Palliative care is integrated into the public health care system, and provided in hospitals, nursing homes and home care. During the last fifteen years, specialist palliative care teams and/or units have been established in all hospital trusts across the country.

Regional centres

Since the start about 20 years ago, the establishment of clinical palliative care services has been linked to research activities. In 2000, regional palliative care centres were set up in each of the country's four health care regions. These Centres of Excellence have an important function in education, training, and service development. They coordinate professional networks, produce guidelines, and audit the services in their respective regions. In addition, the regional centres are the main units for palliative care research. All four centres are linked to the university and the university hospitals in their respective regions, and function as hubs for clinical studies and research training.

The close links between the clinical services and the research units have enabled the regional centres to undertake and coordinate a number of important clinical trials over the years.

PRC European Palliative Care Research Centre



European Research Centre

The European Palliative Care Research Collaborative, EPCRC, was the first major palliative care research project to be funded through the European Commission's Framework Programmes (FP6). The project was coordinated from the Norwegian University of Science and Technology (NTNU) in Trondheim, and involved three of Norway's regional palliative care centres as well as 10 other partners in six European countries. After the successful completion of the project,



Researchers at the Regional Centre of Excellence for Palliative Care, Western Norway. Left to right: Dr. Rae Frances Bell, Postdoc Katrin Ruth Sigurdardottir, Professor Hartwig Körner and Professor Dagny Faksvåg Haugen.

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the European Palliative Care Research Centre was established at the NTNU. The main objectives of this centre are to undertake clinical multi-centre studies and train researchers. The centre has 15 core collaborating institutions in seven European countries plus Canada and Australia, and is closely linked to the European Association for Palliative Care Research Network.

Nationally, the European Palliative Care Research Centre links the Regional Centres of Excellence together in a strong research network, facilitating national and international collaboration. Research is primarily focused on symptom assessment in cancer patients, management of pain and cachexia, and organisation of services.

Western Norway

Even though the regional Centres of Excellence have close collaboration, each centre also has its own profile and specific research areas. The centre in Bergen in Western Norway has a long standing association with the Cochrane Collaboration and the International Association

for the Study of Pain (IASP) Special Interest Group for Systematic Reviews. Dr. Rae Frances Bell is a reviewer for the Cochrane Pain, Palliative and Supportive Care review group in Oxford, UK, specialising in reviews of drugs for pain relief.

Professor Hartwig Körner is a colorectal surgeon investigating different aspects of surgical palliative care.

The centre in Bergen is also the national lead in care for the dying, and an active partner of the International Collaborative for Best Care for the Dying Person.

Research barrier: Describing the study population

Despite advances in recent years, palliative care is still a young and rather limited research field. Several barriers have been identified that need to be overcome to further advance the field. One important barrier is the lack of standards and common methodology in palliative care research.



Patients in many phases of the cancer trajectory may need palliative care. This means that palliative care populations may be very heterogeneous – some patient groups being ambulatory and well-functioning, while others bedbound and close to the end of life. When reading a research report, it is not always easy to identify the characteristics of the population in which the study was performed. Indeed, reviews have shown that in the majority of studies, the subjects are only described by their age, gender, and diagnosis. This means that it is very difficult for the reader to judge whether the results of a particular study are applicable to his or her own patients.

The EAPC Basic Dataset

To overcome the barrier described above, a consensus process was conducted among international palliative care clinicians and researchers, with the aim of developing a basic dataset to describe a palliative care population. This work formed part of Dr. Katrin Sigurdardottir's PhD project. Through an extensive Delphi process, consensus was

obtained on a dataset of 31 demographic and disease-related variables. The dataset has been endorsed by the European Association for Palliative Care and published as the EAPC Basic Dataset. The dataset is currently being piloted in six European countries. We believe that the EAPC Basic Dataset will make an important contribution to improved quality in palliative care cancer research.

Our experience in Norway is that a suitable national organisation, together with structured collaboration and networking contributes to building a strong foundation for high quality research in cancer palliative care.

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Improved cancer care: Integrating palliative care and oncology

Norwegian cancer researchers launch a project to improve care for cancer patients with limited life expectancy

Europe has about 3.5 million new cancer cases per year, and the number is rising. Advances in treatment options have led to more patients getting cured and prolonged survival for those with incurable disease. However, a major concern in cancer care is the rapidly increasing complexity of treatment, which leads to escalating costs threatening the sustainability of the services. One important contributor to this scenario is the increasing use of chemotherapy during the patient's last year of life – often without documented efficacy. Patients receiving intensive oncologic treatment during their final months or weeks have a poorer quality of life than those who receive symptom-directed treatment. Indeed, recent studies show that introducing a palliative care approach at an early stage in patients with incurable disease may improve their quality of life and even prolong survival.

PALLiON

In 2014, Norway's four Regional Health Authorities announced a call for cross-regional research projects to strengthen clinical research and health services research.



The program was administered through the Research Council of Norway, and cancer research was one of the prioritised areas.

Against the backdrop described above, leading researchers in oncology and palliative care submitted a proposal to test the efficacy of an intervention integrating oncology and palliative care services for cancer patients with a life expectancy of less than one year – PALLiON. The proposal was highly ranked and received €3 million (25 million NOK) funding for a five-year project. PALLiON was the only cancer-related study to be funded within this call.

Collaborative effort

PALLiON is designed as a national, multi-centre, cluster-randomised trial. This means that the intervention is performed at an institutional level, with six hospitals forming the 'active cluster' in which the intervention takes place. Six matching hospitals constitute the 'control cluster'. The 12 hospitals have been recruited from all health care regions in Norway and range from small, local hospitals to large university clinics. A total of 550 patients who are receiving chemotherapy and have a life expectancy of less than one year will be included in the study.

PALLiON will be coordinated from Oslo University Hospital, with Professor Jon Håvard Loge as Principal Investigator. The Project Management group has members from the University Hospitals in Bergen, Trondheim, and Oslo, supported by a distinguished international reference group.



PALLiON central project group. Back row, from left: Professor Per Grøttum, Head of Technical Transfer Eivind Andersen, Professor Nina Aass (hidden), Director, Professor Stein Kaasa, Postdoc Tonje Lundebj, Professor Arnstein Finset, Principal Investigator, Professor Jon Håvard Loge, Research Nurse Signe Danielsen. Front row: Project Administrator Torunn Wester, Professor Dagny Faksvåg Haugen, Postdoc Kjersti S. Grotmol, Professor Marianne Jensen Hjermsstad, PhD student Hilde Krogstad and Statistician Cinzia Brunelli. The participants represent Oncology, Palliative Medicine, Medical Informatics, Behavioural Sciences and Communication, Psychology, Medical Statistics and Oncology Nursing, and are affiliated with Oslo University Hospital and the University of Oslo, St Olavs Hospital, Trondheim University Hospital and the Norwegian University of Science and Technology, and Haukeland University Hospital and the University of Bergen.

Complex intervention

The intervention to be tested in the PALLiON study consists of three parts: Systematic electronic assessment of symptoms, implementation of an integrated care pathway, and an educational program for oncologists and palliative care physicians.

Pain, fatigue, loss of appetite and other distressing symptoms are common in patients with advanced cancer. Lack of a systematic assessment has been identified as one of the barriers to effective symptom control. In PALLiON, symptoms will be frequently and systematically assessed by means of EIR, a computer program developed at the European Palliative Care Research Centre (PRC) at the Norwegian University of Science and Technology in Trondheim.

The integrated care pathway gives an outline of the patient pathway, integrating oncologic treatment, palliative care and end-of-life care, and hospital as well as community care. The aim of the pathway is to promote early integration of the palliative care approach, and to reduce the variability in clinical practice.

The educational program is tailored to the other elements of the intervention, but puts the main emphasis on communication, prognostication and symptom management.

Project goals

Combined, the three elements of the intervention are expected to improve symptom management, improve quality of life for the patients and their families, and empower them to play an active part in decision-making. We also hypothesise that the intervention will lead to reduced hospital stays and increased use of community-based care in the final months of life. The main outcome measure of the project will be the proportion of patients treated with chemotherapy in the last three months of life.

The detailed study protocol is under preparation. This also includes assessment of all study sites at baseline. A study organisation has been set up at Oslo University Hospital, and interdisciplinary teams are working on the different elements of the intervention. Local study coordinators and groups are being established at all project sites.

Inclusion of patients will start in September 2016.

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