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Editorial Comment

Palliative care in cancer: How to improve clinical research

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The complexity and opportunities for treatment of patients with cancer have increased greatly over the last decade. The change is primarily caused by the development and marketing of new technologies in screening, pre-treatment diagnosis, as well as curative and life prolonging treatment modalities. Many patients are living longer with or without symptoms from the disease and/or the treatment, while the cure rates have only been influenced marginally.[1] The costs for health care in general and cancer care specifically have increased enormously during the last decade.

The landscape in oncology is therefore changing, more patients are living longer with metastatic disease. Many of these patients are suffering from distressing symptoms, such as pain, depression, cachexia, dyspnoea and sleep problems. Along with the tumour directed treatment, these patients should be properly diagnosed for symptom severity, treated and followed up. Palliative care, including symptomatic treatment, should be included in national oncology treatment guidelines, as a part of each recommendation for the different cancer diagnoses (lung cancer, lymphoma, gastrointestinal cancer, etc.), as well as separate guidelines.[2] In order to reach such a goal oncology and palliative care need to collaborate at all levels from evidence-based guideline development to patient and family care.

Optimal implementation of new technology into a public health care system calls for a safe, sound and robust scientific basis. The effect of the new technology need to be documented, the right patients need to be offered the right treatment at the right time, and the effect on individual as well as on group levels need to be monitored systematically with valid and reliable outcomes.

In the palliative phase of a disease trajectory, the primary goal is to add quality to the days left of a patients' life (that is palliative care), and if possible days or months to the life (that is life prolonging oncological treatment).

All cancer patients in a palliative phase of their disease will need contributions from specialists in oncology, palliative care and family medicine and others in a coordinated action. Clinical coordination means collaboration. Effective collaboration between different specialists in cancer care seems to be most effective if the scientific missions, which each field/speciality is based upon and is clearly defined and acknowledged and ideally the quality of the academic fundaments are equal.

The development of academic oncology from screening through multimodal curative and life prolonging treatment have reached a high quality. In national and international treatment guidelines the clinical evidence is solid for many of the recommendations reaching evidence level A or B.[3] In

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cancer palliative care, however, even in the most frequently investigated symptom, pain, most recommendations are a level C or D, and some recommendations may reach level B or A,[4] although for the service of multiprofessional palliative care teams recommendations are often levels A and B.[5]

In a recent workshop representatives of the academic cancer palliative care environment have proposed a cancer palliative care research agenda in Europe, and identified barriers and solutions to improve cancer palliative care research.[6] The preparations and 'reality orientations' of the participants were based upon previous systematic and non-systematic review, which have identified the lack of consensus regarding definitions and outcomes for the most prevalent symptoms in patients with advanced cancer, such as pain, assessment and classification.[7] In other words, the most basic tools, the outcomes and patient cohort classifications in clinical cancer symptomatology research and clinics are not present. Pain, dyspnoea, cachexia and depression, among other symptoms, are classified (diagnosed) and assessed (measured) differently between and within institutions. For oncology it would have meant that groups of lung cancer patients would not be comparable between studies and institutions, and that the effect of the treatment would be assessed differently between centres.

The workshop initiated through and EU funded coordinated action program – PRISMA – included 30 participants from 25 different countries.[6] Basic research on symptom definition, assessment, classification and treatment were prioritised along with the need for sufficiently designed and sampled intervention studies. A strong 'self reflection' from the workshop is documented in that many of the participants saw potential solutions to improve both quality and quantity of cancer palliative care research within the given organisation and structure. However, a lack of earmarked funding, sustainable academic posts and the need for academic medicine into clinical cancer palliative care were identified as key goals for the near future.

Developments in cancer symptom management specifically and palliative care in general can only happen successfully if there is close collaboration between oncology and palliative care. With oncology far in front academically of palliative care we believe that this collaboration will only improve, if the academic standard and, the research evidence base of palliative care improves significantly. Such an improvement for cancer palliative care can best happen in collaboration with 'mainstream oncology', in the academic institutions nationally and internationally, in planning and running of academic institutions, in each department and in collaboration about the patients who are in need of both specialities.

This workshop outlined a future European research agenda for cancer palliative care in collaboration with the European Association for Palliative Care Research Network (EAPC RN), the newly established academic institutions – the European Palliative Care Research Centre (PRC)[8] and Cicely Saunders International.[9] We believe that goals can be met faster and with higher quality through collaboration between palliative care and oncology organisations.

Conflict of interest statement

None declared.

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