

COMMERCIAL AND SOCIAL DETERMINANTS IN PALLIATIVE CARE

By: Stein Kaasa, Marianne Jensen Hjermstad and Per Sjøgren

Summary: All cancer patients benefit from structured palliative care interventions that are patient-centred, as these demonstrate improved care quality, symptom relief and quality of life. Patient-centred palliative care should be provided alongside tumour-centred care (TCC), rather than the sole TCC-focus on cure supported by the pharmaceutical industry. In practice, this is not the case. Commercial determinants are a prohibitive factor for the integration of patient-centred care (PCC) and TCC. The time has come for joint actions by politicians, the medical industry and professional organisations to consolidate palliative care and PCC as essential parts of cancer care, with the aim of improving quality of life.

Keywords: *Palliative Care, Patient-centred Care, Integration, Commercial Determinants, Symptom Management, Quality of Life*

Introduction

The 1990 World Health Organization (WHO) definition of palliative care emphasised the active approach of palliative care for symptom control in patients with progressive, far-advanced disease and limited life expectancy. Since 2002, subsequent WHO definitions have explicitly recommended the provision of palliative care from early on in the disease trajectory regardless of treatment intention,¹ a request that has not been accomplished. The World Health Assembly resolution on palliative care in 2014 urged national authorities to improve access to and develop palliative care as a core component of health systems. Unfortunately, palliative care is still misconstrued as end-of-life care

only, and is seen as being passive and “not offering hope”, publicly, politically and within health care.

Palliative care is active care, with interventions and examinations that address the needs of patients and families during curative, life-prolonging and end-of-life care. Patient-centred care (PCC) is the mainstay of palliative care, focusing on the *patient*, not the disease. The aim is to provide the best possible symptom relief; physically, psychologically and existentially, and to improve quality of life (QoL). This is achieved by acknowledging the patients’ perceptions and preferences, with early, systematic assessments and treatment. The multidisciplinary approach makes palliative care applicable at all health care levels, corresponding to the

Cite this as: *Eurohealth* 2022; 28(2).

Stein Kaasa is Professor, Marianne Jensen Hjermstad is Senior Researcher, European Palliative Care Research Centre (PRC), Department of Oncology, Oslo University Hospital, and Institute of Clinical Medicine, University of Oslo, Norway; Per Sjøgren is Professor, Department of Oncology, Rigshospitalet, Copenhagen University Hospital, Denmark. Email: marijahj@medisin.uio.no

Table 1: Stakeholder opinions on the commercial and social determinants of health in cancer care

Negative or imbalanced consequences – four main categories	Negative or imbalanced consequences – continued
<p>1. CDoHs shape today's anticancer treatment and highly influence cancer care</p> <ul style="list-style-type: none"> • Economic power and resources of the pharmaceutical industry <ul style="list-style-type: none"> – permits extensive marketing of drugs, conduct of treatment trials – constant promotion of new, expensive drugs, driving costs and demands – continuous development and promotion of new treatments and technologies, i.e. (drugs, radiotherapy, imaging, surgery) – constantly promoting new methods as better and more efficient than well-known technologies – deliberately underscoring that most of these new, advanced therapies are effective only in highly selected subgroups of patients • Patent protection issues delay bio-equivalent products, driving costs up <ul style="list-style-type: none"> – pushing new patented drugs limits access to efficient medications – non-patented, traditional agents launched in new patented formulas 	<p>4. Unfavourable marketing of anticancer drugs</p> <ul style="list-style-type: none"> • Present regulations of industry-driven marketing remain inadequate <ul style="list-style-type: none"> – Imbalanced marketing of expensive drugs with inflated cure rates – Undermining the fact that some drugs are for selected populations only – The constant drive to expand the indications for several drugs – Private companies offer new, often unproven treatments for out-of-pocket payment with high promises, increasing the public demand • Extensive marketing of expensive analgesics with no superior effects compared to affordable and well-tolerated morphine • The dominating marketing of analgesics may downplay efficient pain interventions, such as single fraction radiotherapy when indicated • No ethical imperative to produce low-cost morphine to increase availability
<p>2. A steadily growing and dominating focus on cure</p> <ul style="list-style-type: none"> • A gradual medicalisation of the society at large, with social issues becoming medical issues, as well as in health and end-of-life care with a general marketing of staying young and healthy forever • Most of today's medical funding, from governments, research councils and programs, EU and private charities use this assumption as a bait for funding <ul style="list-style-type: none"> – marketing that most cancers can be cured – little attention towards the heterogeneity of cancer diagnoses and patients – neglect negative consequences of anticancer therapy at end-of-life 	<p>Positive consequences – two main categories</p> <p>1. Substantial advances in cancer therapies</p> <ul style="list-style-type: none"> • The pivotal role of the pharmaceutical industry in the development of anticancer and symptom-relieving drugs leading to: <ul style="list-style-type: none"> – substantially higher cure rates and extended life expectancy for millions of patients for many years – better symptom management, tolerance to treatment, QoL and supportive care – development of analgesics, antiemetics, antidepressants and cachexia[†] drugs (to some extent) have been favoured by industry, and improved symptom management and functioning – world-wide opioid availability, albeit varied accessibility, availability and affordability across countries
<p>3. Key CDoHs in PCC</p> <ul style="list-style-type: none"> • Commercial interests prevent implementation of PCC due to the dominant focus on antitumor treatment, new drugs and technologies • Introduction of palliative and symptom-focused care occurs too late in the disease trajectory, due to more anticancer treatment at end-of-life • Little attention to side effects during and after curative and life prolonging treatment • Few economic incentives related to symptomatic management and psychosocial support • Death and dying attract little attention compared to anticancer treatment • Disproportionate focus, interest and cost allocation between TCC and PCC • The paradox of the iatrogenic* opioid-overuse in some high-income countries alongside insufficient pain management and poor availability/accessibility in many middle and low-income countries • Auxiliary palliative care consultations during pharmaceutical studies are not reimbursed as they are not part of the trials • Palliative care still has a stigma: this is a CDoH enforced by the tumour-centred focus of cancer care, industry and media, influencing both health care professionals and the public • The common perception that any physician/oncologist can provide specialist PCC 	<p>2. Policy regulations and private initiatives</p> <ul style="list-style-type: none"> • Stronger enforcement of marketing regulations in the last two to three decades • Privately run non-profit services and organisations contributing to better cancer care and research

Source: Authors' own survey.

Note: Fifteen of 18 collaborators (83.3%) responded to this email survey.

* Illness caused by medical intervention or treatment.

† a complex syndrome associated with an underlying illness causing ongoing muscle loss that is not entirely reversed with nutritional supplementation.

WHO statement that the competence, attitudes, and skills of palliative care should be integrated in cancer and general health care.²

“Patient-centred care is the mainstay of palliative care”

The dominating focus on medical advances, curation and prolongation of life has gradually increased and led to extended use of anticancer treatment even in advanced stage cancer and in the last weeks or days before death. The numerous cycles of anticancer treatment now being administered for most diagnoses have prolonged survival for millions of people. However, the quality of this treatment would have been substantially better, and more effective, if integrated with a palliative care approach.²

The documented evidence that integration of palliative care and PCC alongside tumour-centred care (TCC) provides considerable benefits in patient-centred outcomes is substantial. Adhering to the individual patient’s needs, experiences and own symptom evaluation results in better physical and emotional functioning, QoL and care satisfaction in patients and caregivers, reduces hospital admissions, and even prolongs survival time.^{2,3} Still, referrals to palliative care occur far too late in the disease trajectory, and PCC and TCC are not universally nor systematically integrated. This does not comply with recommendations and guidelines from WHO, the European Society for Medical Oncology (ESMO), and the American Society of Clinical Oncology (ASCO).²

Commercial, financial, professional and attitudinal barriers hinder this integration. Partly driven by commercial and social incentives, budget allocations are markedly disproportionate, with substantial investments in TCC and anticancer treatment relative to PCC.

The estimated and considerable increase of patients living with cancer underscores the need for change to ensure high quality care to patients and families, acknowledging their voices. A better understanding of how the commercial and social determinants of health (CDoHs) influence the policy of cancer care is necessary. This should guide the development of a model with informed implementation strategies to integrate PCC and TCC, with joint actions by organisations (WHO, European Union), health care providers, the medical industry and politicians.

Stakeholder opinions point to how CDoHs have influenced cancer care and palliative care

We surveyed members of the European Palliative Care Research Centre (PRC) in November 2021 about the commercial and societal determinants pertaining to cancer care, including survivorship care – “cured” or “living with cancer”, palliative care, and end-of-life care. Respondents come from a variety of countries, are renowned researchers, and represent a diversity of medical disciplines and related professions. All respondents have worked for decades in oncology, palliative care, internal medicine, anaesthesiology, neurology or public health. **Table 1** provides an overview of their responses to 24 open-ended questions or statements, divided into four main categories of perceived negative influences, and two about perceived positive influences.

The influence of CDoHs on palliative care development and integration

Poor integration of PCC and TCC

Economic incentives have led to the development of anticancer treatments and advanced imaging technologies for diagnostics, cure and life prolongation. Examples are PET-scanning, cytotoxic targeted agents, immunotherapy and radiotherapy. The corresponding commercial interest in symptom-directed medications has been substantially lower; when present, the underlying intention is to relieve symptoms such as nausea, mucositis or neuropathic pain to increase the tolerance for more anticancer treatment. Thus, the main driver is still TCC, not PCC *per se*. One may actually

argue that the biased focus on new and advanced anticancer treatments totally sets the previously small economic momentum of PCC aside, commercially and publicly.

The assumption that by treating the cancer, the patient will improve is coupled with the similar impetus to treat as long as possible, even if detrimental to the patient. A large registry-based study showed that close to 20% of patients received chemotherapy the last two weeks of life.⁴ For radiotherapy, the financial models incentivise provision of multiple rather than single fractions in patients with incurable metastatic disease and short life expectancy, despite strong evidence of equivalent outcomes, and substantial patient benefits.

To implement PCC, a shift of focus from solely anticancer treatment to the patient perspective and from commercial profit to quality care is necessary. The erroneous impression of PCC, palliative, supportive, survivorship and end-of-life care being self-financed, or at best only needing minor funding, must be challenged.

Moreover, the clever marketing of new anticancer treatments as personalised medicine given their association with certain biomarkers, promotes the impression that the patient is in focus. That is not the case: the tumour is the target. This TCC approach should be merged with PCC that is responsive to patients’ needs throughout the course of treatment. This integration of care actually benefits all parties, and should be promoted and anchored by commercial bodies, NGOs, professional organisations and politicians alike, enforced by adequate resource allocation at all levels.²

Pain management and use of analgesics

This is a clear example of poor universal and human outcomes when commercial interests set the clinical agenda. Commercial determinants have highly influenced the use of analgesics worldwide. In cancer care the pharmaceutical industry has been particularly involved in manufacturing and marketing opioids, which is the mainstay for achieving pain relief and improving the QoL for patients with cancer-related pain.^{5,6}

The first decade of promoting the WHO pain ladder,⁹ introduced in 1986, focused on the favourable analgesic effects of opioids in patients with advanced cancer and a short life expectancy. This contributed to substantially improved pain management in developed countries. Later, the extensive marketing by the pharmaceutical industry in high income countries has led to extended use of opioids for chronic non-cancer pain conditions. Despite the positive analgesic effects for many people, the detrimental effects associated with addiction became increasingly catastrophic over time. An opioid crisis became gradually apparent, with overuse, diversion of drugs, opioid use disorders, and huge numbers of overdose-related deaths particularly in the United States (U.S.). Paradoxically,

regulatory interventions to curb the epidemic also led to a substantial reduction in opioid use in cancer patients near the end-of-life, corresponding to an increase in pain-related emergency room visits.⁹

“Better models for cost containment are needed”

Commercial determinants are definitively in play concerning availability and affordability of analgesics in middle- and low-income countries. In many middle-

and low-income countries, patented opioid formulations with complex delivery mechanisms; i.e. transdermal patches and sustained-release formulations, are subject to intensive marketing to replace the simple, equally effective generic immediate-release morphine agents. Lack of access to morphine that is essential for relief of severe cancer related pain, causes enormous suffering.^{9 10}

Health care spending at the end of life

The increased complexity and overall escalation of costs apply to end-of-life care. This is driven by high-technology interventions, intensive care and anticancer therapies, most with little benefit to patients. The use of these interventions were most pronounced in the U.S., enforced by marketing activities.

Table 2: Recommendations for improvement

Problem area	Operational recommendations
Consensus-based health policy changes are lacking at all decision-making levels, including political, health care and hospital administration, professional organisations, journalists/press	<ul style="list-style-type: none"> • Key policy changes consisting of specific resource allocation, benchmarking and anchoring by responsible parties, policymakers and management at all levels to emphasise the importance of improving cancer care quality • Collaborative promotion of palliative care and PCC as an integrated part of quality cancer care • Provide reasonable resource allocation and financial incentives for delivery of PCC in any relevant setting • Provide incentives other than financial for delivery of PCC; i.e. accreditation programs • Establish firm collaboration between organisations, industry, universities • Promote plenary presentations of integration results at major ASCO and ESMO meetings
Commercial incentives drive medical and technological developments	<ul style="list-style-type: none"> • Regulatory bodies must take action to: <ul style="list-style-type: none"> – reduce biased marketing with promises not accounted for, i.e. inflated cure rates – open for more bio-equivalent drugs, esp. in underserved areas and countries – reduce financial incentives for intensive end-of-life care • Pharmaceutical industry should be required to: <ul style="list-style-type: none"> – incorporate PCC in all clinical studies, without extra funding – invest in studies for regulatory approval of truly palliative indications – support and collaborate in non-pharmaceutical clinical studies
The unilateral focus on cure (TCC) in medical school shapes the professional conduct, and creates attitudinal barriers that are reinforced in clinical practice	<ul style="list-style-type: none"> • Mandatory lectures on palliative care and PCC, in medical school/specialist training • Clinical rotations in palliative care clinics • Promote joint educational activities with other health care professionals to implement the human, person-centred perspective • Establish a medical palliative care speciality
The patient voice does not come across, not in TCC, often also not in PCC	<ul style="list-style-type: none"> • Make adherence to FDA's recommendations on PROMs mandatory in all cancer programs • Include PROMs in prognostic tools to increase precision prior to treatment decisions • Include PROMs results in drug marketing
Palliative care is misconstrued as end-of-life care only	<p>This professional, societal and public opinion can only be reversed by</p> <ul style="list-style-type: none"> • governmental and political initiatives, cognisance and incentives • inclusion in plenary and panel discussions at major professional conferences • emphasis in educational curricula

Notably, overall end-of-life care spending did not differ much between the U.S., Canada and five European countries, with hospital care being the main driver of costs.¹¹ This calls for a change. In today's health care systems, public and private interests compete with one another, as well as with other factors. It's been documented that the probabilities of receiving chemotherapy outside clinical trials during the last month of life were substantially higher in comprehensive cancer centres, private for-profit clinics and centres with no palliative care units than in university hospitals.¹²

Systematic symptom assessment with patient-reported outcome measures (PROMs) is not implemented systematically in cancer care. This inherent part of PCC improves patient care, QoL and tolerance to treatment, is an inexpensive quality indicator and highly cost-efficient as it reduces unnecessary treatment and emergency admissions by 5% to 10%.

Better models for cost containment are needed to examine the societal and individual advantages and outcomes of less intensive anticancer treatment at end-of-life, and professional and societal barriers to palliative care must be challenged. The disproportionate budget allocation between anticancer treatment and palliative care is a major issue, with death and dying not being on the commercial and marketing agenda. A change is needed in the Western world as well as in low- and middle-income countries with poor or no palliative care or symptom relief.^{9 12}

Private health care services

In countries with mixed health provision, i.e. both state and private health care providers, some conditions may not be prioritised for state funding, nor requested, due to a lack of strong advocacy groups for very sick patients. The consequence is effective rationalisation to cut costs. Private providers frequently respond to these market mechanisms, leading to well-developed private oncology practices. However, private insurance companies are less forthcoming about providing private palliative care cover. As a result, the major part of the funding may come

from the charitable sector. Although this allows for a degree of independence and more flexibility in service developments, the funding is more unpredictable and scattered. Further, social inequities in access to palliative care may be reinforced by a higher degree of out-of-pocket payments, albeit also demonstrated as a scarce commodity in countries with national health care. With limited budgets, the never-ending focus on new and expensive drugs is detrimental to overall budgets, a fact that may have positive as well as negative implications for a given palliative care service.

Taken together, this calls for extensive collaborative efforts between industry and health care professionals towards the common goal, better care for cancer patients and families.

Discussion and recommendations

Commercially and societally, it is easy to sell the message – *we will cure cancer*. This is obvious from the major financial contributions from the pharmaceutical industry to cancer hospitals, cancer societies and patient organisations. All bodies promote the cure message, appealing to human nature and emotional states; *“live as long as possible”*, *“I don't want to die”*. Rightfully so, huge investments in new drugs and technologies have led to major improvements in TCC, but not without costs. One is the abyss in the opioid situation with shortage and low access coupled with an overuse epidemic with soaring numbers of death. The intensity of anticancer treatment in the last weeks and days before death is another example, with little or no benefit to patients.

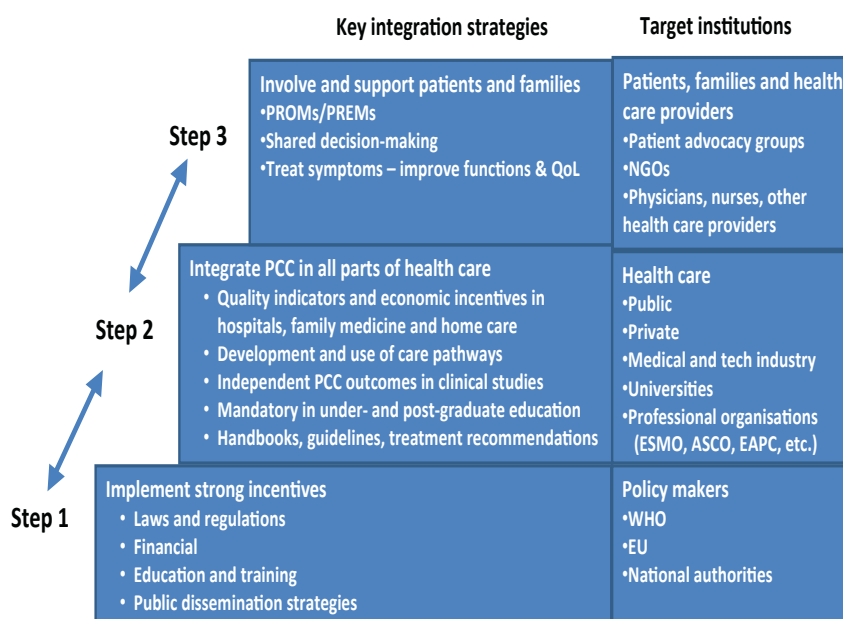
The unidimensional cure focus contrasts professionally endorsed treatment recommendations from ASCO and ESMO, as PCC is perceived as less important, and an add-on to TCC. This perspective disregards that patients and families want *“to live as well as possible”* in the time left. Yet, patients with incurable cancer often have a dual perspective, *“as well”* and *“as long”* as possible. These perspectives vary with disease stage, suffering and time (days/weeks/months) or personal milestones (e.g. living to see

a child's wedding). Provision of integrated PCC and TCC based on patient needs and mutual professional understanding should be mandatory during the entire disease trajectory, fulfilling the holy grail of palliative care; providing the best possible treatment and care to improve QoL, in supportive and palliative care. The key is a closer collaboration between the pharmacological industry and health professionals.

Societal and attitudinal barriers and the overarching perception of palliative care and PCC being synonymous to end-of-life care must be conquered. Palliative care carries a stigma, commercially, publicly, and in the press, that is reinforced by the professional socialisation throughout the medical and nursing education. Direct, targeted and collaborative initiatives are called for in all areas to improve, preferably supported by commercial incentives, policy regulations and mutual understanding among all involved (see Table 2).

A basic premise for integration of TCC and PCC is that PCC is prioritised in budgeting processes. Fixed reimbursements must be triggered and transferred automatically when PCC activities are implemented, according to specific indicators. Examples are: a pre-planned PCC package; place of PCC delivery – i.e. hospital inpatient/outpatient, home, community care; consultation types, e.g. specialist levels, multidisciplinary team, distant electronic monitoring and follow-up etc. Quality indicators for reimbursements may be systematic use of PCC diagnostics such as PROMs in routine care and clinical decision making, family follow-up, time spent at home, and death at the preferred place. Importantly, symptom control is complex and appropriately trained multidisciplinary teams with a clear mission must be recognised as instrumental for success (see Figure 1).

Figure 1 shows the necessary joint actions by target institutions to improve integration of TCC and PCC as well as improving access to palliative care. These include international bodies such as WHO and EU, health care providers and educators at several levels, together with patients and families and their

Figure 1: The Patient Centred Care (PCC) integration ladder

Sources: Authors' own.

interest organisations. Universal access to palliative care must be ensured by legislative regulations and financial incentives. The voice of patients and families must always be acknowledged.

Conclusion

A greater understanding about the influence of CDoHs on cancer care is needed by all parties, followed by explicit actions to address the imbalanced incentives in tumour-centred and palliative/supportive care. The time has come to join forces and develop a model with informed implementation strategies for integrated PCC and TCC to the benefits of patients, families and society.

The authors would like to acknowledge the contributions of: *Lundeby T, Yri O, Dajani O*, Oslo, Norway; *Deliens L*, Ghent, Belgium; *Currow D*, Adelaide, Australia; *Zimmermann C*, Toronto, Canada; *Caraceni A*, Milan, Italy; *Centeno C*, Pamplona, Spain; *Haugen DF*, Bergen, Norway; *Sigurdardottir K*, Bergen, Norway; *Paulsen Ø*, Skien, Norway; *Solheim TS*, Trondheim, Norway; *Higginson I, Stone P*, London, UK.

References

- World Health Organization. *WHO Definition of Palliative Care*. Geneva: WHO, 2013. Available at: <http://www.who.int/cancer/palliative/definition/en>
- Kaasa S, Loge JH, Aapro M. Integration of oncology and palliative care: A Lancet Oncology Commission. *Lancet Oncol* 2018;19:e588–653.
- Bajwah S, Oluyase AO, Yi D, et al. The effectiveness and cost-effectiveness of hospital-based specialist palliative care for adults with advanced illness and their care-givers. *Cochrane Database Syst Rev* 2020; CD012780.
- Rochigneux P, Raoul JL, Beausant Y, et al. Use of chemotherapy near the end of life: what factors matter? *Ann Oncol* 2017;28:809–17.
- World Health Organization. *WHO guidelines for the pharmacological and radiotherapeutic management of cancer pain in adults and adolescents*. Geneva: WHO, 2018. Available at: <https://www.who.int/publications/i/item/9789241550390>
- Cerdá M, Krawczyk N, Hamilton L, Rudolph KE, Friedman SR, Keyes KM. A Critical Review of the Social and Behavioral Contributions to the Overdose Epidemic. *Annu Rev Public Health* 2021;42:95–114.
- World Health Organization *Cancer pain relief* (1 ed.). Geneva: WHO, 1986. Available at: http://apps.who.int/iris/bitstream/handle/10665/43944/9241561009_eng.pdf?sequence=1
- Enzinger AC, Ghosh K, Keating NL, Cutler DM, Landrum MB, Wright AA. US Trends in Opioid Access Among Patients With Poor Prognosis Cancer Near the End-of-Life. *J Clin Oncol* 2021;39:2948–58.
- Knaul FM, Farmer PE, Krakauer EL, et al. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the *Lancet* Commission report. *Lancet* 2018;391(10128):1391–454.
- De Lima L, Arias Casais N, Wenk R, Radbruch L, Pastrana T. Opioid Medications in Expensive Formulations Are Sold at a Lower Price than Immediate-Release Morphine in Countries throughout the World: Third Phase of Opioid Price Watch Cross-Sectional Study. *J Palliat Med* 2018;21(10):1458–65.
- Bekelman JE, Halpern SD, Blankart CR, et al. Comparison of Site of Death, Health Care Utilization, and Hospital Expenditures for Patients Dying With Cancer in 7 Developed Countries. *JAMA* 2016;315(3):272–83.
- Krause R, Nyakabau A, Gwyther LG, Luyirika E, Kaasa S. Calling for advocacy, education and public policy actions on pain control for patients with cancer in Africa. *ESMO Open* 2020;5(4):e000757.