

The integration of palliative care with oncology: the path ahead *

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Abstract: The delivery of comprehensive cancer care within a progressively intricate healthcare environment requires oncology providers to become well-versed in the integration of palliative care (PC). Moreover, as healthcare professionals are urged to prioritize the individual preferences of patients and their families who confront life-limiting illnesses, it has become evident that oncology patients and their families have identified their psychosocial care needs as multifaceted and distinct, calling for specialized attention from care providers. Nevertheless, this is a skill that can be acquired through learning and practice. The landscape of PC is rapidly changing, with paradigm shifting studies highlighting the importance of early concurrent palliative and oncology inpatient and outpatient care for those with new advanced cancer diagnosis. Early concurrent care can notably improve quality of life (QoL), symptom control, patient and caregiver satisfaction, reduce costs and even improve survival. There is no longer a question of if PC should be offered, but instead when referral should be completed, what is the optimal model for service delivery and what barriers are present to achieve concurrent care. Conceptual models have been identified for optimal integrated palliative and oncology care delivery. In order to provide the best integrated care however, multiple obstacles need to be overcome. This narrative review discusses the importance of early integrated oncology and PC for patients with advanced cancer diagnosis, as well as the barriers to the integration of these specialties and potential models for delivery.

Keywords: Palliative care (PC); models of care delivery; early palliative care; integrated care

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Introduction

Background

In the era of modern oncological medicine, almost 50% of the approximately 118,000 cases of advanced cancer diagnosed per year in the United Kingdom (UK) have potentially better survival outcomes (1).

There here exists a broad spectrum of cancer-related symptoms, not only due to underlying disease, but also as a result of toxic treatments used in oncological care. A diverse set of symptoms and their respective severity can be reported by cancer patients including pain, gastrointestinal issues, sleep issues, respiratory issues, fatigue and mood changes (2). Such a prevalence demands a high standard of symptom control.

Rationale and knowledge gap

The landscape of palliative care (PC) is rapidly changing. Initially established in the second half of the 20th century, PC was developed to address the physical, psychosocial and spiritual needs for end-of-life (EoL) patient care with the goal of maximising quality of life (QoL) (3). Oncology and PC traditionally have been closely linked, however in the last decade paradigm-shifting multiple randomised control trials (RCTs) have highlighted the importance of early PC and oncology care integration in improving patient outcomes (4). Whereas previously PC would be synonymous with EoL care for oncology patients, it has now evolved to be provided in early disease trajectory irrespective of prognosis. Notably, this includes PC delivery for patients receiving anticancer treatment, regardless of whether the intent is curative, for palliation of symptoms or survival prolongation (4).

Following a body of evidence supporting the early integration of oncology and PC, the American Society of Clinical Oncology (ASCO) now recommends that all patients with an advanced cancer should be treated by the multidisciplinary PC team within 8 weeks of diagnosis (5). In order to facilitate this, multiple barriers need to be overcome. These barriers include lack of early PC knowledge and referral practices, poor communication between the multidisciplinary team (MDT) and directly with patients, as well as low availability of PC specialists (6). Different models of service delivery need to be considered based on current local and national PC infrastructures, as well as resource availability.

In children, cancer makes up a fifth of deaths and

therefore paediatric PC is a vital and newly emerging medical speciality. There is an unmet need for strong interdisciplinary teamwork to identify and manage distressing symptoms and provide holistic support to patients and their families, however this not in the scope of this review (7).

Objective

The aim of this review is to discuss key elements in PC delivery and the importance of early integration of palliative and oncology care for patients with new advanced cancer diagnosis. Potential barriers to oncology and PC integration, as well as potential models for delivery of integrated care will also be explored.

Discussion

Key elements of PC delivery

One of the key components of oncology and PC are that they involve multidisciplinary teamwork. There are many elements of caring for a patient with advanced cancer which require the integration of highly specialised professionals. The MDT can consist of a diverse group of healthcare professionals including physicians, advanced nursed practitioners (ANPs), physiotherapists and occupational therapists. Additionally, each professional will have varying levels of involvement with the patient and their family, depending on the individual needs and circumstances (8). A team based palliative and oncology approach also helps interdisciplinary team members to comprehensively address the care needs for patients with advanced cancer diagnosis and their caregivers (9). The MDT is able to assess the multidimensional care needs in order to provide holistic patient-family centred care. The PC team also collaborates with other disciplines and services such as social workers, dieticians as well as rehabilitation and support groups (10).

The National Comprehensive Cancer Network (NCCN) highlights the role of the patient's primary oncology team in providing primary PC (10). As such, primary oncology teams need to have to a basic skill set to manage symptoms that are both secondary to anticancer treatment and disease-related. Additionally, primary oncology teams should be able to initiate discussions about prognosis, treatment goals and advance care planning (ACP) (11). This can then be further built upon in collaboration with PC specialists in an interprofessional team. Through this process, primary

Annals of Palliative Medicine, Vol 12, No 6 November 2023

PC initiated by oncology teams can be enhanced and individually tailored to address patient and family needs.

As part of primary PC delivery, regular and early assessment of symptoms is also key. Multiple system assessment tools exist that can aid identification of symptoms that can impact patient QoL such as delirium, nausea, constipation, anorexia, insomnia, anxiety and depression (12). These symptoms can also evolve throughout the disease trajectory. Following identification of symptoms appropriate therapeutic intervention is required.

Early PC delivery for cancer patients

Multiple organisations highlight the importance and support of the early integration of PC in oncological disease management. This includes the World Health Organization (WHO), NCCN and ASCO (5,10,13). More specifically, ASCO recommends that the interdisciplinary PC team should ideally be involved within 8 weeks of advanced cancer diagnosis (5). It is important to note that this concurrent oncology management and early PC is recommended as the standard care for patients who are also on active treatment for their cancer. The NCCN notes that PC can begin at diagnosis and delivered alongside lifeprolonging and disease directed therapies (10).

Several RCTs in patients with advanced cancer diagnosis have exhibited the advantages of early PC input alongside oncology care (14-16). In their landmark RCT, Temel et al. compared outcomes amongst patients with metastatic non-small-cell lung cancer who received early integrated palliative and standard oncology care versus standard oncology care alone. They demonstrated that patients with early integrated care had an improvement in reported QoL, mood, prognostic longitudinal awareness, as well as a reduction in aggressive care towards the EoL. Moreover, the early PC group also had a significantly improved survival of approximately 2 months in contrast to the standard care group (14,17). The finding of improved survival associated with early PC has also been highlighted in the ENABLE III trial, where the 1-year survival rate was improved in the intervention group (16). Interestingly however, the improvement on survival and impact on life expectancy as a result of early PC integration is inconsistent in the literature, with other studies observing no statistical significance on survival (15). PC may facilitate a reduction in symptomatic burden, leading to a stabilisation of the

patient's condition and consequent improvement in survival outcomes. Overall, however, the mechanisms by which early PC integration can confer improved survival are poorly understood and require further research (14).

For inpatients with newly diagnosed advanced cancer or those with an already known diagnosis, improved access to integrated palliative and oncology care can decrease 30-day readmission rates, increase hospice referrals rates and lead to a reduced receipt of chemotherapy post-discharge (18). Use of support services on discharge can also be optimised (18). Earlier inpatient PC team assessment has demonstrated to significantly reduce direct costs incurred during hospital admission. This is thought to be secondary to reduced length of stay and reduced intensity of hospital stay (19,20).

From a holistic perspective, the diagnosis of cancer can be psychologically distressing for patients. Psychological distress can reveal itself in the form of depression and anxiety and is more prevalent for patients with cancer compared to that of the general population. Poor recognition of this psychological burden is associated with reduced QoL (21). The incidence of depression amongst cancer patients is noted to be highest in the acute phase of treatment (22). Possibly contrary to expectations, there is no differences in estimated prevalence of depression in cancer patients receiving EoL care compared to those receiving curative treatment (21,23). Consequently, early palliative intervention can support prompt identification of patients who are either at risk of or actively experiencing psychological distress, which can facilitate timely management.

Early PC integration with oncology care can also have a positive impact on the satisfaction of the patient's family and caregivers. This can include providing social support, emotional care and resources that can assist with the general care of the patient (24). The comprehensive PC assessment should involve the family members of the patient, which contributes to the individually tailored PC management plan (25). Additionally, patient-family centred care promotes active collaboration and encourages shared decision making. Introduction to the PC team early in the patient's cancer journey can foster improved PC team rapport with the patient and family members. Familiarity of services available and enhanced continuity of care can be achieved through early integrated palliative and oncology care, with the collaboration of these specialties further optimising the delivery of coherent and consistent care (26).

Barriers to PC delivery

For patients with advanced cancer diagnosis, there are several barriers to early PC input and the integration of early concurrent palliative and oncology practice. The NCCN highlights that a major reason for delayed PC provision is due to healthcare professional reluctance and confusion surrounding the definition of PC of the general public (10). Notably, confusion regarding terminology is attributed to the perception of PC being synonymous with EoL. This stigma can persist among patients and caregivers despite early PC involvement, which can lead to perceptions of hopelessness, fear and avoidance (27). The misconception of PC can also be a common theme amongst care providers. Although there is consistency in views that PC aims to maximise patient and family QoL, some still perceive it to be only an option for terminal patients after all diseasemodifying treatment lines have been exhausted (28). Given the stigma and existing misconceptions surrounding 'palliative care' terminology, which can consequently delay PC integration, both patients and professionals have previously suggested use of 'supportive care' terminology to be adopted instead (27,29). This terminology alteration has been associated with increased early inpatient and outpatient referrals, thus facilitating earlier access to integrated care (30). Service perceptions can alter use of systems already in-place. Although changes in terminology can be considered, ultimately education of both public and healthcare professionals is essential to enable widespread understanding and appreciation of PC services.

Appropriate education of healthcare professionals can positively impact referral practices to PC services. Oncologists have been observed to predominantly refer advanced cancer patients for the management uncontrolled physical symptoms or anticipated symptoms secondary to disease burden (31). Referrals in the context of poor symptomatic control are frequently completed late in the disease trajectory (32). It is hoped that through dissemination of the new ASCO guidance, healthcare professionals can complete a PC referral early in the disease trajectory (5). Understandably, this raises questions regarding future referral practices of patients with advanced cancer to PC teams, notably that referral should be based on diagnosis and prognosis rather than symptom burden (5). This can be viewed to contradict current clinical practice, where clinicians generally refer patients depending on their clinical needs (33).

Effective communication skills are essential for healthcare

professionals. In PC delivery it plays an important role in discussions regarding prognosis and EoL care issues. Prognostic awareness can be achieved through sensitive discussions with the patient and caregivers. Improvements in the understanding of prognosis is associated with increased implementation of advanced medical directives, reduced hospital inpatient deaths and realistic patient expectations without harming emotional wellbeing (34,35). Patient autonomy and an informed decision-making process guided by the patient's treating oncologist and respective MDT is paramount. However, this can only be achieved through open and honest conversations with the patient. It is also important to appreciate the role of effective interspecialty communication; notably between oncology and PC teams when concurrent care is administered. Collaboration and sharing of resources between specialists are pivotal in order to function in harmony and address the multi-dimensional needs of a patient with cancer diagnosis (36). Given the interdisciplinary nature of PC, good communication within teams is also vital.

From a PC perspective, an increase in requirement for services and the need for earlier engagement in the disease trajectory of cancer patients carries the risk of stretching thin the already highly in demand and under-resourced workforce (37). It has long been accepted that there is a shortage of hospice and PC physicians. Current training capacity has also been noted to be insufficient to meet the future needs of a growing population and increase in service demand (38). As such, this highlights the importance of oncologists practicing exemplary primary PC and the need to adapt to methods used by PC teams (39). Equally from a systems perspective, having an adequate PC delivery infrastructure will be key to meet an increased service demand. The ambulatory nature of oncology means patients are frequently seen in specialty outpatient clinics, whilst PC clinics and providers may be working elsewhere; even at different institutions (37). In the UK, geographic variation and an inequality of access to high quality personalised PC is a continued issue, especially for patients from areas of greater deprivation (40).

PC delivery in the National Health Service (NHS) England and the role of ANPs

PC service delivery in the NHS has evolved throughout the years but remains a complex publicly funded system. PC service provision includes inpatient units, which are voluntary sector-run and NHS-run; hospital support, outpatient clinics, home care services and bereavement support (41). However, nationwide variation in service availability exists; for example, some local centres may offer outpatient PC clinics, whereas others may not. In 2007, the Royal College of Physicians highlighted that there was a reliance on charitable funding, which exacerbates variation in PC delivery and health inequalities across areas with different socio-economic demographics (42). The NHS was noted to fund only approximately 30% of palliative specialist care costs (42).

More recently in 2022, the UK government passed the Health and Care Act [2022], which introduced Integrated Care Systems across England (43). As part of this, Integrated Care Boards were also introduced, which are statutory NHS organisations responsible for the role of managing the allocated NHS budget and provision of NHS services in their local area. It is hoped that with the introduction of these commissioning groups, local PC needs will be appropriately identified and thus facilitate the delivery of high-quality PC for the local population (44). Local variation in access to high quality personalised PC has also been acknowledged and the commissioning groups have been tasked with improving equity of access and outcomes (44).

The increased demand for PC services in oncology and limited institutional resource availability highlights the importance of innovative methods of PC delivery. Notably, the role of ANPs have significantly grown in recent years. ANPs can assist with PC delivery and will play an important role in PC service provision (45). Through day-to-day care with oncology patients, ANPs can gain a first-hand strong understanding of patient values, family dynamics and EoL wishes. They can develop strong relationships with patients and their families (46). This presents an opportunity for ANPs to contribute immensely and take a lead role in palliative and EoL care for the patient.

ANPs work with cancer patients in a variety of settings including in hospital and in the community. At times, they may be one of the first healthcare professionals to initiate PC discussions (47). Consequently, it is imperative that they are appropriately trained in providing basic PC as well possessing the knowledge base to make appropriate specialist referral as required.

Outpatient care delivery

Sustainable outpatient clinic structures play an imperative role in supporting the integration of oncology and PC

services. They can provide patients access early in the disease trajectory to specialist PC services. Additionally, given the ambulatory nature of outpatient clinics, a large number of patients can be accommodated (33). Three different innovative models for outpatient PC delivery have been highlighted by The Center to Advance Palliative Care; stand-alone, co-located, and fully embedded clinics (48). Stand-alone PC clinics operate separately to other specialist clinics, whereas co-located clinics may share workspace, financial costs or clinical staffing with the oncology team. Fully embedded/integrated PC clinics are co-located with the oncology team, but can coordinate treatment protocols, implement common clinical pathways and improve communication between the MDTs (48). These models aid the specialist multidisciplinary PC team to assess to the oncology patient's physical, psychological and spiritual needs to deliver optimum holistic care.

The introduction of the integrated oncology-PC clinic model also presents opportunity for ANPs. Support from ANPs and use of scalable implementation strategies have been shown to improve quality measures of supportive care such as increased multidisciplinary teamwork, higher proportion of ACP and hospice referral practice (49). PC ANP directed intervention with integration to oncology clinics is also welcomed by patients and their families, as well as being associated with improved patient emotional and mental QoL (50).

Embedded PC and oncology clinics operating in shared spaces also have the potential advantage of improving volume and timeliness of referrals, as well as promoting the co-management of patients and the interdisciplinary nature of PC and oncology (33). With consideration of resource and infrastructure availability, the embedded approach also mandates allocation of clinical space for the PC team within the oncology clinic. Practically, for patients this model can reduce trips to hospitals and wait times. It is also anticipated that with the geographic proximity to the oncology team, there could be a destigmatisation of the referral process to PC from both a patient and clinician perspective (9).

Disadvantages of embedded clinics include constraints in space and time for PC input in the oncology clinic. Logistically, in large cancer centres there may be multiple tumour site-specific oncology clinics, thus there is a risk of fragmentation or overstretching of services if care is required simultaneously across multiple clinics (9,51). On the other hand, in smaller centres a question of cost effectiveness is raised owing to low volume of referrals.

As noted, in comparison to embedded clinics, the

multidisciplinary PC team stand-alone clinics function independently in its allocated clinic space. The Princess Margaret Cancer Centre in Toronto, Canada, for example operates with this model (51,52). There are 12 free-standing rooms available for their PC clinic operating 5 days a week staffed by the multidisciplinary PC team. PC services offered included scheduled appointments, urgent same-day appointments, nurse lead telephone triage line and afterhours physician telephone support (52). The evidence base for stand-alone clinics is strong, with multiple RCTs supporting the early integration of palliative and oncology care using this model (14,15,51). Additionally, they offer customized space for patients, greater scope for expansion and more autonomy regarding clear and consistent referral criteria (9). However, from a financial perspective, freestanding clinics can incur greater start-up costs and budgetary considerations will need to be made (9).

Overall, when considering embedded versus stand-alone clinic models in outpatient PC delivery, potential advantages and disadvantages of each delivery method needs to be considered. It is also important to note evidence supporting embedded clinics over non-embedded clinics is limited and more research is required to determine superiority in terms of PC outcomes, access and cost (33). Each Integrated Care Board of the NHS will need to decide which model of outpatient PC delivery is optimum to facilitate the integration of oncology and PC services in their local area. As with other hospital services difficult decisions will be made around resource availability, local care infrastructures, long-term financial viability and arguably most importantly; needs of their local population demographic.

Facilitating the integration of oncology and PC

Heterogeneity exists in healthcare delivery, patient population, clinical training and the understanding of the role of PC management in advanced cancer. Multiple integration models exist for facilitating the integration of concurrent oncology and PC. These include the time-based model, which focusses on the chronological integration of care alongside disease progression, and the providerbased model that offers primary, secondary or tertiary level PC depending on patient care needs (53). The issuebased model, a more onco-centric approach, highlights the benefits and drawbacks of solo, congress and integrated care approaches. At present, this oncologist driven referral pattern for patients with advanced cancer is most prevalent worldwide (33). A system-based model takes on a more patient-centric approach and involves automatic referral based on clinical events (53).

Automatic referrals with the use of predefined selective criteria such as time of diagnosis, prognosis and individual care needs can streamline referrals, offering a high degree of PC access (33). The automatic triggering of PC referral based on prognosis and diagnostic criteria is supported by multiple RCTs (14-16). It goes without saying, for this to be successful adequate resource allocation and appropriate PC infrastructure is essential. Selective criteria for referral trigger needs be dynamic and be at equilibrium with local resource availability and individual patient needs on regular assessment. These models can be harnessed to promote integration of oncology and PC services from a local to national scale. Within the NHS, local infrastructures and resources will need to be assessed by Integrated Care Boards in order to determine viability of such models locally.

In practice, ASCO recommends the use of the TEAM (time, education, assessment and management) approach (39). The first component the TEAM-based approach involves Time; a monthly structured PC visit should be implemented that lasts at least an hour. Notably this can be undertaken by ANPs, who can also support the general advancement of palliative and oncology care integration (46). As mentioned previously, patient Education regarding prognosis, symptom control and ACP are pivotal. More than two thirds of patients with incurable stage IV lung and colorectal cancer thought their palliative chemotherapy would be curable (54). Use of formal assessment tools should be implemented to facilitate the identification of physical symptoms, psychological distress, or spiritual distress that otherwise might not have been picked up on. Patient management guided by the MDT is also key (39). The use of embedded versus stand-alone clinics can be considered. Co-location and the physical integration of the fully functional interprofessional PC team alongside the oncology clinic can aid specialty integration (55).

Strengths and limitations

This narrative review serves as a foundation for discussion but is subject to certain limitations. Given its nature as a narrative review, our primary focus was on identifying the most pertinent research to substantiate any assertions regarding the role of early PC delivery for cancer patients, barriers to PC delivery, PC delivery in the NHS England and the role of ANPs, outpatient care delivery, and the

Annals of Palliative Medicine, Vol 12, No 6 November 2023

integration of PC with oncology. It is worth noting that this field is evolving rapidly, emphasizing the importance of comprehending the practices and viewpoints of healthcare professionals who deliver PC services. This understanding is crucial for enhancing the timely delivery of PC.

Conclusions

The role of early integrated PC is essential in the management of patients with advanced cancer diagnosis. It encapsulates a holistic way of ensuring patients have an improved QoL. Looking ahead, PC should be viewed as an essential component of early management for patients with an advanced cancer diagnosis, rather than something to be introduced when treatment options have been exhausted. Symptom management matters, and improves patient outcomes and QoL, regardless of the stage of their cancer.

As such, in order to manage the inevitable increase in demand for PC services, investment in developing outpatient clinics and training ANPs will be important. Models of outpatient delivery need to be explored by stakeholders and advantages of respective models for delivery must be harnessed to reach their potential. Increased research into outpatient delivery models can further guide this decision-making process. Efficient and effective models for integrated general service delivery need to be established from a local to national level with sufficient PC infrastructure and adequate resource allocation.

Overall, multiple barriers need to be overcome in order to guide the early integration of palliative and oncology care for patients with advanced cancer. From education to resource availability, barriers to concurrent management need to be tackled so that the best possible care can be provided for our patients.

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1380

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