INFORMAVENETO

Marzo 2021

RINNOVO DELLA QUOTA DI ADESIONE ALLA SICP

Desideriamo ricordare a tutti coloro che non lo avessero ancora fatto che è possibile rinnovare la quota di adesione alla SICP per il 2021. Le nuove adesioni e i rinnovi si potranno fare solo sul sito internet della SICP.
Maggiori informazioni sulle quote di adesione e sulle modalità di pagamento sono disponibili su pagine dedicate del sito Internet della SICP (www.sicp.it).
Per qualsiasi chiarimento o per verificare la propria posizione contributiva non esitate a contattare la segreteria:

Telefono: 02 29002975
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SAVE THE DATE

ASSEMBLEA REGIONALE ELETTIVA 2021

16 APRILE 2021

NOTIZIE DAL CONSIGLIO DIRETTIVO

SALUTI DA PARTE DEL COORDINATORE

Dopo quattro anni si conclude il mandato dell'attuale consiglio direttivo. Il nuovo consiglio verrà eletto e si insedierà il 16 Aprile 2021.

Sono stati anni di fermento e novità. In particolare, ricordo l'approvazione a livello regionale della DGR. 553 del 30/04/2018 riguardante i percorsi di cura per le cure palliative dell'adulto che ha permesso l'attivazione delle U.O.C di Cure Palliative in tutte le AULSS della regione.

E' stato questo il primo passo verso una nuova visione e organizzazione delle cure palliative. Il futuro ci apre a nuovi scenari e nuove prospettive, in particolare per quanto riguarda la cronicità. Sarà pertanto un futuro volto all'implementazione di una cultura di cure palliative trasversale e aperta alle varie figure professionali e specialità. In tal senso, diviene fondamentale promuovere percorsi formativi e sviluppare processi decisionali condivisi che sostengano le decisioni cliniche affiancandole ad una valutazione etica metodologicamente strutturata.

Durante questi anni sono stati promossi numerosi convegni e iniziative formative con il coinvolgimento anche del mondo del volontariato che oggi rappresenta un elemento centrale nel contesto delle cure palliative. Abbiamo cercato di promuovere al meglio i rapporti con SICP nazionale e con le associazioni di volontariato. Si è cercato di lavorare in maniera unitaria su procedure e istruzioni operative facendo tesoro dell'esperienza di tutti. Infine, ricordo la pubblicazione della NewsLetter, un'iniziativa "editoriale" periodica, che vorremmo potesse continuare nel tempo con il contributo di tutti.

Il futuro ci vedrà tutti impegnati in alcuni passaggi fondamentali quali l'accreditamento delle reti di cure palliative, la formazione e il reclutamento di nuovo personale e, non ultimo, la ricerca in cure palliative. In quest'ultimo ambito, come società scientifica, abbiamo un ruolo non derogabile che necessita del contributo di tutti.

Chiudo questo breve saluto con alcuni ringraziamenti.

Un ringraziamento al direttivo nazionale e al presidente, nonché alla segreteria di Milano che ci ha sempre supportati nelle varie iniziative dandoci suggerimenti utili e preziosi consigli.

Un grazie va a tutti i nostri direttori delle U.O.C. del Veneto, ai responsabili degli hospice e a tutto personale che lavora a livello regionale nell'ambito delle cure palliative, auspicando che si possa costruire, con il contributo di tutti, un modello di rete sostenibile e realmente centrato sui bisogni delle persone. Grazie a tutti anche per l'impegno e la dedizione profusi in questi mesi di periodo covid.

Infine, due parole di riconoscimento e ringraziamento a tutto il consiglio direttivo di SICP Veneto, un gruppo di professionisti ma soprattutto di amici che ha sempre collaborato con disponibilità e dedizione. Grazie a Claudio, segretario attento e sempre presente. Grazie a Giuliana e Luca per il loro contributo professionale e per la disponibilità. Grazie ancora a Roberta e Paolo, palliativisti con la "P" maiuscola e, infine, un grazie a Mirko, medico dal cuore grande e che, per primo, ha proposto e voluto scommettere su questa NewsLetter.

Buon lavoro al nuovo direttivo

Dott. Giovanni Poles

PROPOSTE BIBLIOGRAFICHE

Integration of oncology and palliative care: a *Lancet Oncology* Commission

Stein Kaasa, Jon H Loge*, Matti Aapro, Tit Albreht, Rebecca Anderson, Eduardo Bruera, Cinzia Brunelli, Augusto Caraceni, Andrés Cervantes, David C Currow, Luc Deliens, Marie Fallon, Xavier Gómez-Batiste, Kjersti S Grotmol, Breffni Hannon, Dagny F Haugen, Irene J Higginson, Marianne J Hjermstad, David Hui, Karin Jordan, Geana P Kurita, Philip J Larkin, Guido Miccinesi, Friedemann Nauck, Rade Pribakovic, Gary Rodin, Per Sjøgren, Patrick Stone, Camilla Zimmermann, Tonje Lundeby*

Full integration of oncology and palliative care relies on the specific knowledge and skills of two modes of care: the tumour-directed approach, the main focus of which is on treating the disease; and the host-directed approach, which focuses on the patient with the disease. This Commission addresses how to combine these two paradigms to achieve the best outcome of patient care. Randomised clinical trials on integration of oncology and palliative care point to health gains: improved survival and symptom control, less anxiety and depression, reduced use of futile chemotherapy at the end of life, improved family satisfaction and quality of life, and improved use of health-care resources. Early delivery of patient-directed care by specialist palliative care teams alongside tumour-directed treatment promotes patient-centred care. Systematic assessment and use of patient-reported outcomes and active patient involvement in the decisions about cancer care result in better symptom control, improved physical and mental health, and better use of health-care resources. The absence of international agreements on the content and standards of the organisation, education, and research of palliative care in oncology are major barriers to successful integration. Other barriers include the common misconception that palliative care is end-of-life care only, stigmatisation of death and dying, and insufficient infrastructure and funding. The absence of established priorities might also hinder integration more widely. This Commission proposes the use of standardised care pathways and multidisciplinary teams to promote integration of oncology and palliative care, and calls for changes at the system level to coordinate the activities of professionals, and for the development and implementation of new and improved education programmes, with the overall goal of improving patient care. Integration raises new research questions, all of which contribute to improved clinical care. When and how should palliative care be delivered? What is the optimal model for integrated care? What is the biological and clinical effect of living with advanced cancer for years after diagnosis? Successful integration must challenge the dualistic perspective of either the tumour or the host, and instead focus on a merged approach that places the patient's perspective at the centre. To succeed, integration must be anchored by management and policy makers at all levels of health care, followed by adequate resource allocation, a willingness to prioritise goals and needs, and sustained enthusiasm to help generate support for better integration. This integrated model must be reflected in international and national cancer plans, and be followed by developments of new care models, education and research programmes, all of which should be adapted to the specific cultural contexts within which they are situated. Patient-centred care should be an integrated part of oncology care independent of patient prognosis and treatment intention. To achieve this goal it must be based on changes in professional cultures and priorities in health care.

La presa in carico da parte della rete di Cure Palliative è stata identificata come uno dei maggiori determinanti di appropriatezza clinica nel fine vita oncologico e riduzione del ricorso a strutture per acuti. Purtroppo il processo di transizione del paziente dalle cure oncologiche, tipicamente ospedaliere, alle cure di fine vita territoriali è uno snodo particolarmente fragile dal punto di vista sia clinico-relazionale sia organizzativo. Viene richiesto il coordinamento tra diversi servizi, un network professionale solido e il rispetto degli strumenti proposti dalla legislazione vigente per l'attivazione dei servizi domiciliari. Sono stati identificati tre elementi chiave volti a garantire al paziente una continuità di cure oncologiche integrate e coordinate durante tutto il decorso della malattia: l'organizzazione efficace dei servizi e del flusso dei pazienti tra gli stessi, la condivisione delle informazioni e il rafforzamento di comunicazione e cooperazione multiprofessionale e multidisciplinare. Il rischio è che l'organizzazione di questi passaggi sia talvolta poco efficace, causando ritardi o mancate attivazioni del servizio di Cure Palliative anche a fronte di bisogni complessi e sopravvivenza dei pazienti spesso limitata. L'articolo, che potete trovare in esteso in allegato, approfondisce quali siano le migliori modalità di integrazione tra oncologia e cure palliative allo scopo di assicurare una vera continuità di cura per i nostri pazienti.

Dott. Mirko Riolfi

SEGNALAZIONI DALLE ULSS VENETE

CURE PALLIATIVE NEI CENTRI SERVIZI PER ANZIANI

Nel mondo occidentale la percentuale di anziani con oltre 65 anni che vivono in CSA varia dal 2 % al 8%, tale valore sale al 20% se si considerano gli ultra ottantacinquenni e di questi la maggior parte si trova ad affrontare un periodo più o meno lungo di fine vita prima della morte. A titolo di esempio, nella sola Olanda, ogni anno il 34% dei residenti nelle "Nursing Home" entra in fase di fine vita.

In linea generale i pazienti che decedono nelle residenze per anziani possono essere affetti da patologie oncologiche e da patologie cronico-degenerative (tra cui la demenza di diversa origine) che portano a una perdita delle funzioni motorie e cognitive (compresa la capacità di comunicare i propri sintomi e le proprie sofferenze) in uno spazio di tempo variabile, a volte anche molto ampio, con episodi di aggravamento che si alternano a periodi di relativa stabilità.

La necessità di fornire anche agli ospiti dei CSA un adeguato riconoscimento e trattamento dei sintomi rappresenta quindi una crescente necessità, sia che si tratti di persone in grado di comunicare i propri bisogni, sia che si tratti di persone affette da demenza di vario grado con una capacità di comunicazione più o meno compromessa.

La Legge n. 38 del 15 marzo 2010 **"Disposizioni per garantire l'accesso alle cure palliative e alla terapia del dolore"** tutela il diritto di tutti i cittadini ad accedere alle cure palliative e alla terapia del dolore, per ogni età, per ogni patologia, per ogni luogo di cura a tal fine impegna le strutture sanitarie ad assicurare un programma di cura individuale per il malato e per la sua famiglia, senza alcuna discriminazione, al fine di tutelare la dignità e l'autonomia del malato, promuovendo la qualità della vita fino al suo termine.

Secondo questa legge, le strutture sanitarie devono assicurare un programma di cura individuale per il malato e la sua famiglia, nel rispetto dei seguenti principi:

- Tutela della dignità e dell'autonomia
- Tutela e promozione della qualità della vita fino al suo termine
- Sostegno sanitario e socio assistenziale alla persona malata e alla famiglia.

Lo strumento operativo che ha il compito di garantire, organizzare ed erogare le Cure Palliative è la **Rete Locale di Cure Palliative** che comprende strutture Ambulatoriali, Residenziali Ospedaliere e Residenziali del Territorio e fra queste le Residenze Sanitarie Assistenziali.

In questi termini le Strutture Socio Sanitarie ed Assistenziali devono attivarsi per far si che anche i propri residenti ricevano cure palliative appropriate nella fase di fine vita e del morire.

Partendo da queste premesse l'AULSS 1 Dolomiti, Mano Amica, l'Azienda Feltrina per i Servizi alla Persona e l'APSP "Valle del Vanoi" hanno realizzato un progetto per l'implementazione delle cure palliative in questo setting spesso dimenticato. Potete trovare il progetto per esteso in allegato.

Segnalazione a cura del dott . Giampietro Luisetto

EVENTI E FORMAZIONE

ASSEMBLEA REGIONALE ELETTIVA 2021

Gentili Soci,
con la presente, vi comunichiamo che l'Assemblea Regionale Elettiva 2021 è convocata per il giorno 16 aprile 2021, dalle ore 18:00 alle ore 19:00, con il seguente ordine del giorno:

1) Rinnovo delle cariche
2) Saluto e obiettivi del nuovo Consiglio Regionale
3) Varie ed eventuali.

Il link per il collegamento all'Assemblea, mediante piattaforma ZOOM, sarà inviato dalla Segreteria il giorno stesso dell'Assemblea elettiva.

Quest'anno l'appuntamento è di particolare rilevanza in quanto ci sarà il rinnovo delle cariche del Consiglio Regionale (Coordinatore e Consiglieri), che avverrà con elezioni che si terranno mediante piattaforma (Eligo) Venerdì 16 aprile 2021 dalle ore 11:00 alle ore 17:00.

Le credenziali di accesso all'area di voto saranno inviate ai Soci mediante mail direttamente da Eligo. Sarà sufficiente che il Socio apra la mail e segua la procedura indicata, che prevederà due distinte votazioni (per il candidato Coordinatore e per i Consiglieri). I risultati saranno comunicati in Assemblea dal Coordinatore.

Si ricorda che i Soci aventi diritto di voto sono coloro che sono in regola con la quota SICP dell'anno in corso (2021) e approvati da almeno 120 giorni, rispetto alla data dell'Assemblea. Ai fini organizzativi non saranno ammessi alla votazione i Soci che non risulteranno in regola con la quota associativa 2021 entro e non oltre cinque giorni lavorativi prima della data definita per l'Assemblea elettiva.

In allegato potete trovare il PDF della convocazione dell'Assemblea, inviato ai Soci per Mail il 12 Febbraio 2021.

EVENTI E FORMAZIONE



SALUTI DEL XVIII Congresso Nazionale SICP (dal sito www.SICP2021.com)

Un anno fa, nei saluti del "**XXVII Congresso Nazionale SICP**" dedicato alle Cure Palliative del futuro, ci si chiedeva "Cosa vogliamo che succeda?". La risposta crediamo di averla trovata ed è rappresentata dalle Reti di Cure Palliative, Regionali e Locali.
Reti da rafforzare o da costruire ex novo. Reti fatte di persone, professionisti e volontari, integrati e organizzati. Reti capaci di dare risposte ai bisogni vecchi, ma anche a quelli nuovi dettati dalla pandemia e dagli effetti che questa ha prodotto su tutto l'ambito socio-sanitario. Reti in grado di progettare e di fare, ma anche di monitorare e di misurare. Reti pronte ad impegnarsi, in questo tempo sospeso ma anche nel futuro prossimo, nelle sfide clinico assistenziali per tutte le persone malate con bisogni complessi e parallelamente disponibili a fare propria la responsabilità di una necessaria evoluzione scientifica attraverso una crescita dell'attività di ricerca.

Le Cure Palliative sono ormai un diritto, una disciplina, un livello essenziale di assistenza e una specializzazione medica. Come palliativisti c'è bisogno di partire dalla consapevolezza di quello che siamo e soprattutto di quello che ci rende unici: saper essere presenti in ogni setting assistenziale, condividere e creare connessioni, individuare i bisogni e costruire percorsi assistenziali personalizzati e appropriati, comunicare tra specialisti e professionalità diverse, mettere la persona malata al centro, rispettarne dignità e facilitarne l'autodeterminazione. Solo così potremo continuare ad incidere sulle politiche sanitarie, attraverso competenze solide e un'identità sempre più forte che faccia della multi-professionalità e della capacità di dialogo e di apertura, l'elemento centrale su cui rafforzare la costruzione della Reti. Anche quest'anno, oltre ai temi clinici, assistenziali, organizzativi, psicologici e relativi alle humanities si è scelto di aggiungere il tema delle nuove emergenze legate alla pandemia da Covid. Le Cure Palliative stanno mostrando di saper esistere e resistere anche di fronte alle difficoltà estreme dettate dalla pandemia e da qui partiremo per nuove riflessioni sempre più ampie, concrete e coraggiose.

Al momento attuale l'andamento della pandemia non ci permette ancora di definire se il Congresso si svolgerà in forma virtuale o in presenza a Riccione o se sarà un evento ibrido. I molti feedback rispetto al gradimento della scorsa edizione vogliamo leggerli come volontà e desiderio dei soci e di tutti i professionisti sanitari interessati e coinvolti nelle Cure Palliative di esserci nonostante tutto e questo rappresenta un fortissimo stimolo a fare sempre meglio per la crescita di SICP. Abbiamo bisogno, ora più che mai, di buone idee e soprattutto di buone pratiche perché siamo davvero convinti che le Cure Palliative siano una buona notizia in sé, per le persone malate, i loro cari, la Medicina e il Sistema Sanitario. Spetta a ognuno di noi far sì che, in quanto tale, riesca a contaminare positivamente tutto ciò che gli sta intorno. I Board del Congresso sono già al lavoro, ma attendiamo i vostri preziosi contributi, mossi dall'obiettivo di offrire a tutti coloro che lavorano nel nostro ambito una grande opportunità di crescita culturale e scientifica.

Gino Gobber (presidente del Congresso)
Marta De Angelis (Coordinatore del Board Scientifico)
Luciano Orsi (Co-coordinatore del Board Scientifico)

Consiglio SICP Veneto

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Per segnalazioni
e proposte scrivete a
Mirko Riolfi.

Il prossimo numero di
InformaVeneto SICP
sarà pubblicato in
Giugno 2021

ALLEGATI

- Convocazione Assemblea Elettiva SICP Veneto 2021
- Articolo: Integration of Oncology and Palliative Care: a Lancet Oncology Commission
- AULSS1 Dolomiti: Progetto Cure Palliative nei CSA

SICP
Società Italiana di Cure Palliative®
VENETO

Venezia-Mestre, 12 Febbraio 2021

Sede regionale SICP Veneto

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Alla cortese attenzione

Dei SOCI della
SOCIETA' ITALIANA DI CURE PALLIATIVE
Regione Veneto

Oggetto: convocazione Assemblea Regionale Elettiva 2021

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I risultati saranno comunicati in Assemblea dal Coordinatore.

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Cordiali saluti

Il Coordinatore (G.Poles)

Il Segretario (C.Ferro)

Consiglio Regionale 2017-2020

Coordinatore
Giovanni Poles

Segretario
Claudio Ferro

Consiglieri
Claudio Ferro
Luca Furlanetto
Giuliana Menegaldo
Roberta Perin
Mirko Riolfi
Paolo Sandri

Consiglio Direttivo Nazionale 2020-2024

Presidente: Gino Gobber, Vice Presidente: Grazia Di Silvestre; Segretario: Simone Veronese, Tesoriere: Rita Mar
Consiglieri: Raffaella Antonione, Stefania Bastianello, Marta De Angelis, Edoardo Di Maggio, Giampaolo Fortini, Luca Manfredini, Past President: Italo Penco

Integration of oncology and palliative care: a *Lancet Oncology* Commission

Stein Kaasa, Jon H Loge*, Matti Aapro, Tit Albreht, Rebecca Anderson, Eduardo Bruera, Cinzia Brunelli, Augusto Caraceni, Andrés Cervantes, David C Currow, Luc Deliens, Marie Fallon, Xavier Gómez-Batiste, Kjersti S Grotmol, Breffni Hannon, Dagny F Haugen, Irene J Higginson, Marianne J Hjermstad, David Hui, Karin Jordan, Geana P Kurita, Philip J Larkin, Guido Miccinesi, Friedemann Nauck, Rade Pribakovic, Gary Rodin, Per Sjøgren, Patrick Stone, Camilla Zimmermann, Tonje Lundeby*

Full integration of oncology and palliative care relies on the specific knowledge and skills of two modes of care: the tumour-directed approach, the main focus of which is on treating the disease; and the host-directed approach, which focuses on the patient with the disease. This Commission addresses how to combine these two paradigms to achieve the best outcome of patient care. Randomised clinical trials on integration of oncology and palliative care point to health gains: improved survival and symptom control, less anxiety and depression, reduced use of futile chemotherapy at the end of life, improved family satisfaction and quality of life, and improved use of health-care resources. Early delivery of patient-directed care by specialist palliative care teams alongside tumour-directed treatment promotes patient-centred care. Systematic assessment and use of patient-reported outcomes and active patient involvement in the decisions about cancer care result in better symptom control, improved physical and mental health, and better use of health-care resources. The absence of international agreements on the content and standards of the organisation, education, and research of palliative care in oncology are major barriers to successful integration. Other barriers include the common misconception that palliative care is end-of-life care only, stigmatisation of death and dying, and insufficient infrastructure and funding. The absence of established priorities might also hinder integration more widely. This Commission proposes the use of standardised care pathways and multidisciplinary teams to promote integration of oncology and palliative care, and calls for changes at the system level to coordinate the activities of professionals, and for the development and implementation of new and improved education programmes, with the overall goal of improving patient care. Integration raises new research questions, all of which contribute to improved clinical care. When and how should palliative care be delivered? What is the optimal model for integrated care? What is the biological and clinical effect of living with advanced cancer for years after diagnosis? Successful integration must challenge the dualistic perspective of either the tumour or the host, and instead focus on a merged approach that places the patient's perspective at the centre. To succeed, integration must be anchored by management and policy makers at all levels of health care, followed by adequate resource allocation, a willingness to prioritise goals and needs, and sustained enthusiasm to help generate support for better integration. This integrated model must be reflected in international and national cancer plans, and be followed by developments of new care models, education and research programmes, all of which should be adapted to the specific cultural contexts within which they are situated. Patient-centred care should be an integrated part of oncology care independent of patient prognosis and treatment intention. To achieve this goal it must be based on changes in professional cultures and priorities in health care.

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See Comment page e565, e568, e570, and e572

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Introduction

The overall aim of this Commission is to show why and how palliative care can be integrated with oncology for adults with cancer, irrespective of treatment intention, in high-income and middle-income countries. This integration will combine two main paradigms, tumour directed and patient (host) directed, through the use of the most effective and optimal resources from oncology and palliative care in well-planned, patient-centred care pathways.

The two paradigms might be understood to be representing two different cultures. Oncology has roots in mainstream medicine (ie, internal medicine), and is primarily based on the acute care model. From the mid 1960s, hospice and palliative care were established outside the main health-care systems, often financed by charities. At the time, the primary focus of palliative care was end-of-life care, with care provided by multidisciplinary teams working with patients and their families. Now, for the most part, oncological and palliative care cultures are still separate.

Research on integrating oncology and palliative care is heterogeneous. Almost all studies have been done in high-income countries, but the variation across countries, systems, and settings often limits the generalisability of findings. The 2018 *Lancet* Commission report on palliative care focusing on low-income and middle-income countries stated, "Poor people in all parts of the world live and die with little or no palliative care or pain relief."[1] That Commission gave a series of recommendations, such as how to quantify serious health-related suffering, and proposes an Essential Package of palliative care, which might also be relevant to high-income countries as a basic benchmark of successful implementation at the patient level. Their previous Commission also recommended international and collective action to receive universal coverage of palliative care and pain relief, and better evidence and

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priority-setting tools to measure the global need for palliative care and implementation policies. Given the empirical basis presented in the 2018 *Lancet* Commission, the recommendations are primarily focused on high-income countries, but the findings, experiences, and models presented might be highly relevant to other contexts as well.

The WHO definition of palliative care states that the competence, attitudes, and skills of palliative care should be integrated in health care in general and in cancer care, "Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, and is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life."[2] The present paper accepts, but builds on this definition, which differs substantially from the common perception of palliative care as being synonymous with end-of-life care.

Hospital-based specialised palliative care alongside tumour-directed and life-prolonging treatment has been shown to contribute to better oncology care for patients and families, in terms of better symptom management, quality of life, satisfaction with care, and less psychological distress; some studies even suggest survival benefits.[3–5] Thus, we think it is timely to rethink and reorganise the delivery of oncology and palliative care to improve treatment and promote collaboration at the appropriate levels of care. We propose models of integration that fit the tasks and responsibilities of the two main hospital categories—ie, university hospitals (tertiary) and local hospitals (secondary), and community health care (primary).

Integration of care is a complex intervention based on organisational structure and patient-centred plans. The use of standardised care pathways (SCPs) is a method or planning tool for the implementation of such complex processes. The European Pathway Association (EPA) defines SCPs as "a complex intervention of the mutual decision making and organisation of care processes for a well-defined group of patients during a well-defined period". SCPs facilitate transitions within hospitals and between health-care levels, which should be seamless, to ensure the continuity and coordination of care. The present Commission proposes the use of SCPs as a method for the integration of oncology and palliative care.

Supportive care and palliative care focus on the patient—the host of the cancer—whereas the primary focus in oncology is on the tumour. During the past 15 years, semantic discussions have been had regarding definitions and distinctions between supportive and palliative care. The European Society for Medical Oncology (ESMO) states that supportive care should be available at any stage of the disease, whereas palliative care is focused on treatment when cure is no longer possible.[6] The American Society of Clinical Oncology (ASCO) does not specify a particular time for delivery of one or the other,[7] and neither ESMO nor ASCO differentiate between the content of supportive care and palliative care. Despite a similar focus, the starting points for palliative and supportive care differ; whereas palliative care started as end-of-life care, supportive care initially focused side-effects of anticancer treatment, such as chemotherapy-induced nausea and vomiting, and neutropenia. The overall goal of palliative care is to improve the patient's quality of life congruent with the patient's preferences—ie, the patient (host)-centred perspective. Thus, improvement of function, optimal symptom management, mobilisation of resources and active involvement of patient and family throughout the care process are key components. This improvement can be achieved by an integration of oncology and palliative care guided by the patient's needs

Symptom management is a key element of both supportive and palliative care. Symptoms inform diagnosis and treatment in all parts of medicine, and play a central role throughout the disease trajectory. They are a particular focus in palliative care, in that symptom alleviation is the main target for interventions.[2] Symptom assessment is often not done systematically in oncology practice or not routinely incorporated into the clinical decision-making processes.

WHO defines integrated health services as "the organization and management of health services, so that people get the care they need, when they need it, in ways that are user-friendly, achieve the desired results and promote value for money".[8] In oncology, the multidisciplinary team approach that combines competence and skills in the planning of treatment care has become standard.[9] This approach is an integration of disciplines at the hospital level of care (eg, among surgeons, oncologists, pathologists, radiologists, and specialist nurses). The multidisciplinary team can include palliative care specialists at any stage of the disease trajectory, irrespective of whether treatment intention is curative, life-prolonging, or palliative. Given the definition of palliative care, interventions provided by palliative care have a broad focus and can therefore not be delivered by a single profession; multiple professions organised in teams are therefore common. The composition of the teams might vary, depending on local resources and traditions, and the internal organisation of the teams might also vary, but multidisciplinarity, which draws on knowledge from different disciplines but stays within their boundaries,[10] are probably the most common internal organisation. The term multidisciplinary teams will therefore be used throughout this Commission.

From a societal, ethical, and political perspective, the escalating costs of health care are a major problem. Although spending on cancer care comprises only 5% of the overall health-care budget,[11] these costs continue to rise more rapidly than in other health-care areas.[12] The escalating costs can be attributed to the ageing of the population, new and expensive diagnostic and treatment

options, more prolonged survival of patients with metastatic disease, and a growing public demand for tumour-directed treatment at all stages of the disease. The increased complexity and escalating costs also apply to care at the end of life; about a third of the cost of cancer care is spent during the patient's last year of life.[13] Planning and structure of cancer care and palliative care has the potential to reduce costs, especially when the complexity of treatment and care increases.[14]

Evidence-based medicine is the norm in oncology practice, but evidence as to when to start and stop anticancer treatment near the end of life has been scarce.[15] The quality and quantity of research in this area has been questioned.[16,17] This also applies to research on the effects of newly registered targeted therapies and immunotherapies. There is little scientific evidence for the effect of chemotherapy in most areas of symptom management, including the treatment of pain,[18] although palliative radiotherapy might be highly effective in that regard.[19]

It is especially important during the patient's last year of life that the attention given to the effect of tumour-directed treatment is congruent with the individual patient's perception of benefits, in terms of symptom burden and quality of life.[20] Few, if any, trials give guidance for such choices. This has led to the recommendation that a set of criteria (eg, disease progression, performance status, nutritional status, weight loss, and symptom burden) should guide the discontinuation of tumour-directed treatment.[21,22] These criteria could also apply to phase 1 trials, which might have therapeutic intent, but for which the likelihood of benefit to the individual patient might be extremely small.[23] As the disease progresses, the main outcomes of treatment should be continually assessed and redefined as they vary from tumour response to symptom control, preservation of function, and wellbeing.[24]

Shared decision-making (SDM) is a key element of cancer care, but the degree to which patients can participate as active partners in the decision-making process has been questioned, when multiple options for tumour-directed treatment are available and when life-prolonging treatment with marginal benefits are offered.[25] Some patients want to live as long as possible and are willing to try intensive treatment, even if the likelihood of benefit is extremely small and the risk of side-effects that might impair quality of life and reduce residual time at home is high.[26] Active patient participation presupposes sufficient and relevant knowledge of the disease and treatment options. This amount of knowledge can only be reached by the continuous provision of realistic patient-centred information. To provide this information, good communication skills among the oncologists and palliative care specialists are required, and the needs and wishes of patients and families need to be assessed systematically and used in the decision-making processes.[27] For decision making for phase 1 trials, fundamental components of communication and information sharing, including discussion of prognosis and options for supportive care, are often missing from interviews.[28] A more patient-centred focus might be enhanced by a multidisciplinary team approach, with systematic collaboration among team members from different professions within and across levels of care. This implies an empathic approach by health-care professionals with willingness and skills to assess and understand the patient's needs. Health-care providers need to understand, accept, communicate, and plan for home care because most patients want to spend as much time as possible at home during their last phase of life.

Palliative care and oncology care—development over the past four decades

In this section we briefly outline the developmental and conceptual issues of relevance to the present focus on integration of oncology and palliative care. For years cancer care has been criticised for its disproportionate focus on the tumour, compared with attention to the patient with the cancer. The concept of hospice care, and later palliative care, was introduced partly as a reaction to the absence of a patient-centred focus. Attention to palliative cancer care emerged in the 1970s, partly through efforts of researchers such as Jan Stjernswärd, who was attached to WHO at that time.[29] The term palliative care was probably first coined by the Canadian surgeon Balfour Mount in 1974.[30] At the time, palliative care had a strong focus on end-of life-care and it is commonly still equated with this timeframe,[31] despite its subsequent redefinition. A dichotomised perception of oncology care and palliative care is outlined in figure 1. This perception fits with palliative care as equal to end-of-life care, but is not in line with the present definition of palliative care as formulated by WHO ("applicable earlier in the disease trajectory").[2] A perception in line with this definition, in which the two are integrated or given in parallel, is outlined in figure 1.

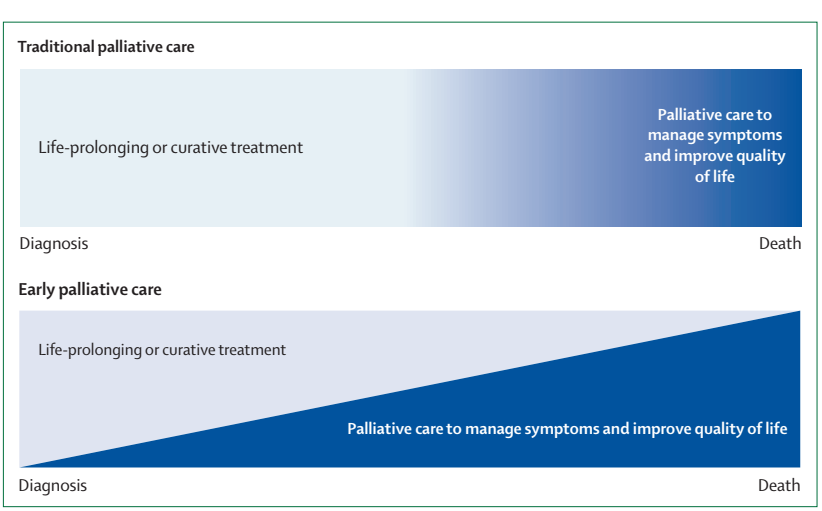


Figure 1: **Traditional versus early palliative care**

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For the **European Pathway Association** see http://e-p-a.org/

Supportive care emerged as a concept and care approach in the late 1980s, somewhat later than palliative care, but with a similar focus on the individual patient with cancer, the host, not the tumour.[32] Supportive care focused on the entire disease trajectory, including when curative treatments, often accompanied by multiple side-effects, are still being delivered. Late effects began to receive attention during the 1980s as new health problems in cancer care, and spawned the field of cancer survivorship, which can be regarded as an extension of supportive cancer care.[33,34]

The difference between palliative care and supportive care is primarily related to differences in the stage of disease to which they are applied, rather than to the treatment itself.[35] This is reflected in the similar definitions of the concepts by the US National Cancer Institute (NCI) and WHO.[36] According to the WHO definition, palliative care focuses on patients with a life-limiting disease, whereas supportive care is applicable irrespective of treatment intention and might also include rehabilitation of cured cancer survivors. Therefore, in our view, treatments of pain, fatigue, physical, and psychological distress after curative treatment are best characterised as supportive care.

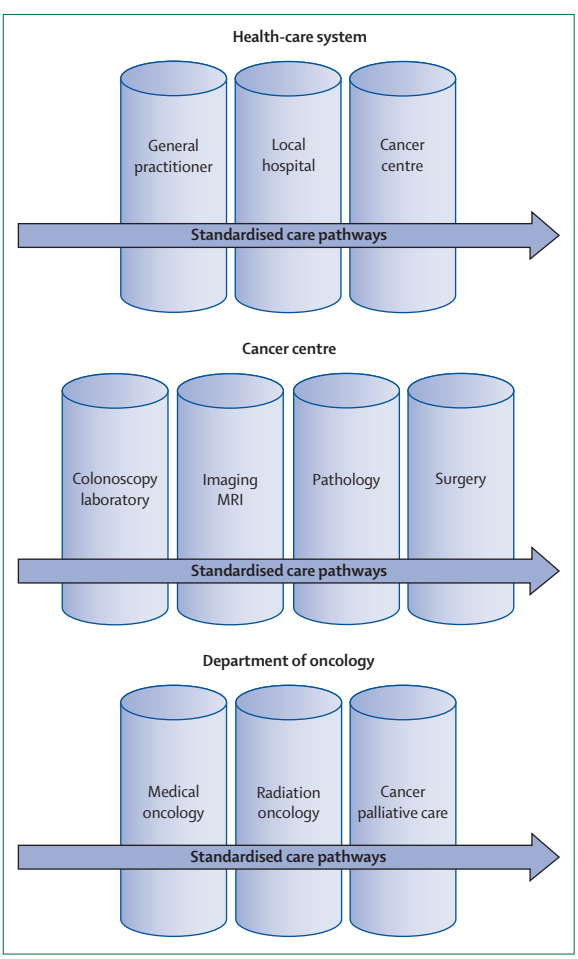


Figure 2: **Health care includes silos at different levels**

The content and professional competence needed to provide palliative care and supportive care are similar, with both focusing on the host—the patient living with the disease or with side-effects after the treatment, or both. Palliative care and supportive care are differently organised across locations, on the basis of resources and traditions. In some centres, the two are organised as one service, whereas in others they are completely separate. Independent of organisational structure, the focus on the host with a patient-centred focus is similar. Therefore, when resources permit, integration of palliative care and supportive care might be most effective in terms of treatment delivery and as a direction to strengthen the patient-centred culture in cancer care delivery.

WHO's most recent (2002) definition of palliative care, revised from its 1989 definition, points to the integration of oncology and palliative care by stating, "Palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications."[37] The integrated care model has also become a topic in cardiology, pulmonology, and other specialties.

Patients live longer with metastatic disease—the need for coordination and planning

The possibilities for tumour-directed treatments have increased exponentially during the past decade. Multiple treatment lines have become the rule for common cancers, such as breast, lung, colorectal, and prostate cancer, and many more patients are now living with metastatic disease. New immune therapies are being introduced to standard oncology care, with side-effects that differ from those of traditional chemotherapeutic agents. We do not have systematic data on the effect of these new therapies on the host and their clinical presentations; however, we do know that the increase in the number of patients living with advanced disease will have implications on coordination and planning of care, and will require the combination of tumour-centred and the patient-centred approaches.

This development has reshaped cancer into a chronic illness, with WHO recognising cancer as one of four major chronic diseases in 2010.[38] The development has also made the terms curative and palliative tumour-directed treatment even more vague and prone to misunderstanding by patients and possibly some medical staff. We prefer terms related to treatment intention; ie, curative, life prolonging, or palliative.[39] An increasing number of patients with advanced cancer will probably die from other comorbid diseases after a prolonged period of tumour-directed treatment; thus, the chronic care model will become increasingly relevant for oncology–palliative care. However, the traditional disease model still dominates within cancer care. The chronic care model was launched at the end of the 20th century,

and represents a paradigm shift within health care.[40] The model emphasises patient-centred elements (eg, patient empowerment, patient preferences, and family and social support)[40] and therefore has obvious similarities with patient-centredness, although the two seem to have been developed in parallel.

Integration in health care

The availability of new tumour-directed treatments for advanced cancer points to a basic challenge in health care in general and in cancer care specifically: how can complex care pathways be organised in a flexible and optimal structure, involving multiple professionals working simultaneously or in parallel? Health care is currently most often organised in silos of primary, secondary, and tertiary levels of care, with levels within each silo as well. Surgical oncology, medical oncology, radiation oncology, and palliative care within the cancer centre are examples of such silos, organised with separate leaders from different departments with individual budgets. Patients and their families might experience great difficulty navigating between and within each of these silos, and understanding mixed messages about the main focus of care presented by two different cultures within the same department or hospital. As exemplified in figure 2, these silos should be connected to provide the varying needs for care of each individual patient. SCPs can be used to foresee, establish, and administer such connections.

In 2007, the WHO Director-General Margaret Chan stated, "We need a comprehensive, integrated approach to service delivery. We need to fight fragmentation."[41] The current challenge to service delivery is the specification of the nature of integrated services in different settings, and the establishment of how integration can contribute to the intended aim of ensuring that patients with cancer, and their families, receive the care they need. The WHO technical brief[8] on the integration of health services aimed to show that integrated service delivery is best seen as a continuum involving technical discussions about tasks that need to be done to provide good-quality health.

Integration aims to coordinate the activities of professionals, with the overall goal of improving patient care. The achievement of such coordination requires change at the system level on the basis of a common understanding and acceptance of the two paradigms in this context. From an organisational perspective, the flow of patients between levels, or silos, of the organisation (ie, units, sections, departments, or hospitals) needs to be taken into account. To reach the goal of integration, a common understanding of a merging of the two paradigms, as well as budgetary reallocations and formal or informal changes in the organisation, are probably needed. These changes might allow more flexible allocation of human and treatment resources according to the needs defined in the SCPs.

***Panel 1:* Three levels of integration**

Linkage

- Patients are cared for in a planned system
- Based on an understanding of special needs (formalised in a standardised care pathway)
- Work in parallel or in series
- Basic understanding of the various professional skills

Coordination

- Patients are cared for in a well-structured plan, on the basis of patients' needs and the content of the standardised care pathway
- Integration operates in separate structures within a system (eg, pathology, imaging, surgery, radiation, or tumour-directed chemotherapy symptom management)
- Integration has been an implementation plan (of the standardised care pathway) and follow-ups and monitoring of the plan

Full integration

- Resources (competence and skills of medical staff) are pooled into one unit or section, taking from existing systems
- Silos are eliminated (partially or totally) and the organisation is based on the standardised care pathway
- The multidisciplinary team meetings can, as a dynamic structure, be an example of full integration as they meet

Panel adapted from Leutz.[42]

In an influential article, Leutz[42] defined integration as "the search to connect the health care system with other human service system to improve outcome (clinical, satisfaction and efficiency)". He proposed three levels of integration: linkage, coordination, and full integration. In panel 1, examples and understanding of these three levels are provided from a general health-care perspective and from an oncology or palliative care perspective, or both. The levels of integration can be understood as both static and dynamic. Integration as outlined in this panel challenge the internal life and individual priorities in cultures and subcultures in both oncology and palliative care. To reach achievable and practical solutions, integration can be formalised and made routine in some situations (eg, multidisciplinary team meetings as one component in a planned structure [SCPs]), or added according to patient needs to optimise care in other situations.

Integration of oncology and palliative care

The term integration has been applied to the interplay between oncology and palliative care for decades; it was used by Malin in 2004,[43] in an editorial that recommended efforts be made to bridge the gap between oncology and palliative care to provide better care for those dying from cancer. The distinction between

	Jordhøy et al (2000)[47]	Temel et al (2010)[3]	Zimmermann et al (2014)[5]	Bakitas et al (2015)[48]	Maltoni et al (2016)[49]	Temel et al (2017)[50]	Grønvold et al (2017)[51]
Clinical structure							
Palliative care inpatient consultation team	Y	Y	Y	Y	..	Y	Y
Palliative care outpatient clinic	Y	Y	Y	Y	Y	Y	Y
Community-based care or home palliative care	Y	..	Y	..	..	..	..
Clinical processes							
Multidisciplinary specialised palliative care team	Y	Y	Y	Y	Y	Y	Y
Routine symptom screening in the outpatient oncology clinic	..	..	..	..	..	..	..
Administration of systemic cancer therapy (eg, chemotherapy and targeted agents) possible in patients admitted to palliative care service	Y	Y	Y	Y	Y	Y	Y
Follow prespecified palliative care guidelines	Y	Y	..	..	Y	Y	Y
Early referral to palliative care	Y	Y	Y	Y	Y	Y	Y
Availability of clinical care pathways (automatic triggers) for palliative care referral	..	..	..	..	..	..	..
Palliative care team routinely involved in multidisciplinary tumour conference for patient case discussions	..	Y	..	..	..	..	..
Communication, cooperation, and coordination between palliative and oncology service	Y	Y	..	..	Y	..	..
Routine discussion of prognosis, advance care planning with goals of care	Y	Y	Y	Y	Y	Y	Y

Y=presence of component in trial. Table adapted from Hui and colleagues.[44,52]

Table 1: **Components of integration from seven randomised trials**

integration and early integration has not been clearly defined, but use of early integration might help to counteract the commonly held belief that palliative care is equivalent to end-of-life care. The strong focus on integration in contemporary oncology and palliative care has also led to experts formulating consensus-based indicators of integration.[44]

Temel and colleagues' findings[3] of improved survival and better quality of life with early palliative care has paved the way for the integration of palliative care in oncology as a means to provide better and more patient-centred care for patients with a life-limiting cancer. Palliative care has also been proposed as a means to offset the rapidly increasing costs in oncology, especially in the patients' last year of life, and to address the anticipated shortage of resources due to increasing demands and costs. Temel and colleagues' study[3] led to the formulation of an ASCO provisional clinical opinion in 2012,[45] which was revised into a clinical practice guideline in 2017.[15] Without using the term early integration, the provisional clinical opinion stated palliative care is more than end-of-life care, and that patients would benefit from receiving palliative care while still receiving tumour-directed treatment, based on a low to medium amount of evidence.[45]

The current research on integration of oncology and palliative care primarily stems from studies of patients with cancer in outpatient hospital settings, and this research has been synthesised in a 2017 review.[46] Other published reviews of the effectiveness of specialised palliative care have mainly been based on mixed populations, without separation of the results for patients with cancer. The trials included in the 2017 review were published between 2001, and 2016, and all used different designs and endpoints. The components of integration from the seven randomised trials included in the 2017 review are shown in table 1.[44,52]

At the turn of this century, Jordhøy and colleagues[47] published the results of a cluster-randomised trial of palliative care. We are not aware of any randomised trials on the effects of palliative care programmes before this publication. Some trials in the 1980s and early 1990s tried to evaluate the effects of elements included in palliative care, such as end-of-life care, with negative results.[53–55] These early trials were hampered by methodological shortcomings, such as an absence of well-defined primary endpoints, control contamination, and problems with the recruitment processes, and problematic attrition and adherence. In their large study[47] of mixed cancer diagnoses using well-validated instruments, Jordhøy and colleagues circumvented many of these limitations; however, the main focus of this comprehensive trial was integration of community and hospital care for patients with advanced cancer. More patients died at home in the intervention group, compared with the control group, and these patients also spent less time in hospitals and more time at home and in nursing homes. No effect on symptom burden was shown, which was reported in a separate article.[4]

Several years later, Bakitas and colleagues[56] designed ENABLE II, a randomised trial to test a telephone-based psychoeducational palliative care intervention delivered concurrent with oncological treatment. The programme was found to significantly improve both mood and quality of life in a sample of 322 patients with mixed cancer diagnoses. However, a traditional palliative care model was not applied, because the study did not systematically include the intervention of a (multidisciplinary) palliative care team.

Temel and colleagues' study[3] is usually referred to as the landmark trial of integration of oncology and palliative care. They showed, among patients with newly diagnosed lung cancer, early palliative care not only reduced depression and symptom burden, and improved quality of life, but also produced a survival benefit. The intervention group reported improved prognostic awareness and received less intensive cancer treatment at the end of life. However, the study was carried out in a highly specialised institution and some researchers have raised doubt as to its generalisability to other care settings.[57]

In a cluster-randomised trial in 2014, Zimmermann and colleagues[5] investigated early involvement of specialised palliative care in the treatment of patients with a wide range of advanced cancers. This study provided evidence of benefits on quality of life and symptom burden, and was the first study to explore clinician-patient interactions, by specifically addressing the relationship with health-care providers and patients' problems in their interactions with nurses and doctors (related to information seeking and communication). The intervention group was more satisfied with care than the control group, but no differences were found in other measures of patient-staff interactions.

In the meantime, the initial model constituting ENABLE II had been expanded, and, in 2015, Bakitas and colleagues[48] published the findings of the ENABLE III trial. Through the application of a fast-track design, this trial was the first to evaluate the optimal timing for the concurrent introduction of palliative care and standard oncological care.[48] The only difference between the groups was longer 1-year survival for the group who received care early compared with the group who started palliative care 3 months later. The intervention consisted of an initial in-person palliative care consultation by a certified palliative care physician, followed by six structured phone coaching sessions by an advanced practice nurse using standardised curriculum. This type of intervention raises the question of whether ENABLE III is a sophisticated psychoeducational model, rather than a specialised palliative care intervention.

In 2016, in a multicentre randomised trial, Maltoni and colleagues[49] evaluated early palliative care efficacy for patients with advanced pancreatic cancer through both patient-reported outcomes and health-care use. They reported benefits in quality of life, symptom burden, and reduced time spent in institutions. As such, this was the first European trial to confirm the results of the important North American trials.[3,5]

Temel and colleagues' 2017 study[50] again drew attention to early palliative care by examining the effect of an integrated palliative care model on patients with newly diagnosed gastrointestinal (non-colorectal) cancer and patients with lung cancer. In addition to improved quality of life and decreased depression, they showed that an integrated palliative care model improved the patients' ability to cope with their prognosis and enhanced their communication with clinicians about end-of-life preferences. They showed that these positive effects vary by cancer types, but the two subsamples were too small to substantiate these differences.

The 2017 Danish palliative care trial (DanPaCT)[51] investigated the effect of a palliative care intervention among patients with a range of cancer diagnoses. Patients were included if they scored above a predefined threshold for self-reported symptoms or reduced functioning. The primary outcome was defined as the individual patient's main problem, as defined by a screening process. The sample was large with little loss to follow-up. No differences in either primary or secondary outcomes were reported. Grønvold and colleagues[51] proposed several possible explanations for the absence of beneficial effects, including the absence of structure in the palliative care visits and short observation time.

A 2018 study[58] confirmed Temel and colleagues' 2010 findings;[3] however, the intervention was not palliative care per se, but consisted of monthly sessions with a palliative care nurse and inferred more use of consultations with a psychologist. The study therefore adds to the variability in the content of the palliative services (ie, the intervention) and of how palliative care and oncology care are delivered in studies of integration of oncology and palliative care,[59] but the added element was patient centred, which is of particular relevance in this context.

The growing body of evidence for integration of oncology and palliative care has been synthesised in reviews, statements, and guidelines, some of which focus specifically on integration and others more generically on specialised palliative care.[15,57,60–62] Several issues complicate attempts to evaluate and compile this literature. Most of the reviews underline that the heterogeneity in settings, target populations, and study outcomes make it difficult to directly compare trials. The diversity in intervention content and the palliative care-specific component are particularly cumbersome (table 1). In addition, the variability in methodological quality across trials was highlighted in a 2016 meta-analysis.[63] When only trials with low risk of bias were considered, the authors concluded that the evidence for the effectiveness of specialised palliative care interventions for improving quality of life and symptom burden is relatively weak.[63] However, a 2017 Cochrane review[64] concluded that early palliative care might have more beneficial effects on quality of life and intensity of symptoms among patients

with advanced cancer than among those given usual or standard cancer care alone. The effects are of clinical relevance for patients at an advanced disease stage with limited prognosis, when further decline in quality of life is the rule.

The heterogeneity in study outcomes and methodological quality of studies of the effectiveness of palliative care are obvious limitations in research on integration. However, although the evidence for integration of oncology and palliative care might seem meagre, the recommendation to integrate is strong because the overall picture shows that different kinds of early palliative care interventions have a positive effect on various patient outcomes.

Systematic symptom assessment

To facilitate better patient involvement in cancer care and improved patient-centred outcomes, the patient's voice must be heard by their medical team during shared decision-making, in terms of symptoms, functions, quality of life, and preferences for information provision. The recognition of the patients' perspectives by health-care providers as valuable or even decisive when choosing how to care, where to care, and when to care, represents a major shift in medicine over the past 10–20 years. Patients' perspectives have now been recognised as valid outcomes in clinical medicine, as endorsed by the National Institute of Health consensus conference.[65] Although systematic symptom assessment is an established core clinical activity in palliative care, directly derived from the WHO definition, symptom assessment is still rarely done systematic or actively used in the patient decision-making processes in oncological and palliative care practices.

In 2006, the US Food and Drug Administration (FDA) proposed the term patient-reported outcomes measures (PROMs) for all measures that can best, or only, be assessed by asking the patients themselves.[66] By that, the FDA also formally recognised the importance and clinical utility of PROMs by releasing a new guideline for industry on these issues. PROMs are therefore an umbrella term covering the patient's perspective on physical and psychological wellbeing, and symptoms and treatment effects.[67] The recognition of PROMs as independent outcomes in cancer[68,69] is consolidated by the CONSORT-PRO extension statement[69] developed to improve the reporting of PROMs on patients' evaluation of symptoms, functioning, and quality of life. Because the patient is the primary source of information, PROMs supplement clinical observations and objective findings with individual patient information.

Symptom assessment tools are, for these reasons, grouped under the umbrella PROMs, which also encompasses other outcomes assessed similarly, such as quality of life and functional status. Symptom assessment is pivotal for palliative care and supportive care efforts throughout the disease trajectory, and increasingly so as life-prolonging, tumour-directed treatment ceases. The infrequent assessment of symptoms is a major factor explaining inadequate symptom relief, with undue suffering among patients with cancer who are approaching end of life. A key symptom in health care is pain, and, according to the international definition by the International Association for the Study of Pain,[70] pain can only be assessed reliably and validly by self-report, not by observations. Several other symptoms, only assessable by patient report (ie, as PROMs), are important to consider in the care of patients with cancer. These include psychological symptoms (eg, anxiety and depression) and somatic symptoms (eg, anorexia, dyspnoea, fatigue), and overall quality of life.

Traditionally, PROMs were collected through the use of paper-based questionnaires. Advances in health information technology have prompted the development of electronic tools for the distribution of PROMs. Such tools allow an effective integration of patient-related data from various sources, and permit follow-up from a distance of patients who are not admitted to hospital or seen in consultations, and can promote data sharing between care teams at different care levels. In oncology, electronic assessments and rapid presentation of results facilitate communication, are perceived positively by patients and clinicians, and might result in a more efficient and focused use of time.[71,72] Further, a 2012 qualitative study[73] showed perceived usefulness of an electronic tool might be more important than functional aspects such as user-friendliness and speed to encourage its use. Immediate display of easily interpretable results to the health-care providers is a crucial factor for successful implementation of electronic registration of PROMs into the clinics.[74]

On the basis of this background information, we find it pertinent to point to a 2016 study[75] on the effects of systematic symptom assessment by tablet computers in patients with advanced solid tumours. The study showed positive outcomes of systematic symptom assessment in oncology practice, and that health-related quality of life improved among the intervention group and worsened among those receiving usual care. In a separate letter,[76] the authors showed improved survival among those who had their symptoms assessed systematically. The results of this trial are a strong reminder of the importance and positive effects of systematic symptom assessment in cancer care in general.

Standardised care pathways

Integrated care models can be understood as organisational methods to solve the challenges of management of complex care processes, and particularly so in the growing elderly population. In integrated care, professionals with different competencies and from distinct organisations work together in complex and formalised structures. This model challenges the traditional vertical organisation of health care, as outlined earlier, structured in pillars or silos.

Patients often experience gaps between services when they must shift to a new level of care or specialisation.[77] A different matrix is hypothesised to better meet the patient's needs, which are complex and shifting over time, and to allow the patient to move between care levels or specialisations in way that is more predictable and transparent to the patient and to their care providers. For this to occur, communication and collaboration among the health-care providers must also be predictable and clearly understood, with the roles of team members clarified and agreed on.

The achievement of integration among the different services and levels of health care is by no means straightforward, because two different cultures with different foci—ie, the tumour-centred and patient-centred pathways—need to join forces and attend to the patient's needs during the development and implementation of the SCPs. Indeed, the greater the number of actors involved in a patient's care, the more difficult the communication and coordination. The development of SCPs is a method for meeting these challenges.

With roots in the automobile and production industries, multiple SCPs have been developed and published over the past 5 years, covering a wide area of health services, ranging from surgical procedures to complex disease trajectories.[78] Implementation of SCPs ensures care is organised with the right people, at the right time, in the right place. Therefore, SCPs can work as a systematic way to organise integration in the organisation to improve patient care and resource use; however, such organisation requires the possibility of seamless patient flow in a customised organisational model.

A wide range of methods have been used in the development of SCPs, mainly without a common framework or international consensus on how to develop them in a standardised and evidence-based way.[79,80] The generalisability of findings is also limited by the plethora of study designs, settings, and proposed pathways. This situation makes the relevance of individual studies difficult to evaluate and apply to clinical settings that are different from the one in which the specific SCP was developed and tested.[81] In their review, Rotter and colleagues [7] assessed the effects of SCPs on professional practice, patient outcomes, and hospital costs. They included 19 randomised trials comparing SCPs to standard practice, based on more than 3000 abstracts identified in their search, covering a wide range of medical conditions and surgical procedures. Of the included trials, nine gave some description of how the SCP was developed and implemented. In those nine studies, the method applied to develop an SCP was mainly described in general terms—eg, a protocol was developed by a multiprofessional team. Ten studies did a follow-up on how health-care providers complied with the SCP protocol, but none were done in a similar way. Only one trial described how relevant clinical outcomes were monitored in the SCP group through the use of computer technology.[82] A main feature of the included trials was that the SCP was applied in a facility-specific manner for a defined period of time, disregarding other elements involved in patient care and follow-up. Because the SCPs tested were mainly paper based, the potential utility of a common and flexible electronic SCP was not evaluated. The way in which different SCPs were audited was also highly variable.[81]

Conclusions

There is now a strong consensus for integration of oncology and palliative care in contemporary cancer care. The newly released ASCO guidelines on the topic were, for months, the most searched article in the *Journal of Clinical Oncology*.[15] The published randomised trials on the subject point to health gains resulting from integration, but what, when, and how to integrate are yet to be established. Despite clear recommendations for integration, this Commission has not identified any health-care system where the content and the constructs of integration are implemented. This Commission will work on the assumption that broad implementation plans are needed, adapted to national, regional, and local organisations of oncology and palliative care, as well as the culture of the organisation. Local variations, in terms of resources and practices, also probably play a role.

By acknowledging integration of oncology and palliative care as a complex process including different parts of the health-care system, both horizontally and vertically, and involving the patient, we propose SCPs as a means by which future efforts could promote integration. For the same reasons, this Commission will address integration in different sections. Each section will address different aspects of integration, ranging from how to focus on the patient, to societal changes and new research areas.

This Commission is an international collaboration between 30 experts in oncology, palliative care, public health, and psycho-oncology. In October 2016, a kick-off meeting was held in Milan, Italy, where panel leaders were appointed, the structure of the commission was decided, and a plan for the work was agreed on. During the 2 years that followed, each panel was expanded with experts within the relevant field, topical literature searches were done, and experts participated in an interactive writing process. Both administrative and academic organisations were run, from Norway, by Stein Kaasa, Jon Håvard Loge, and Tonje Lundeby.

Policy—challenges and frameworks

Demographic data show cancer incidence and prevalence are rapidly increasing, and that the population is ageing with multiple chronic comorbidities. A 2014 study[83] presenting various models for extrapolation in high-income countries found that 69–82% of those who die need palliative care. Consequently, an augmented need for palliative care at all health-care levels is expected.

Palliative care has been identified as an integrated part of the cancer care pathways by professional international organisations such as ASCO, ESMO, and the European Association for Palliative Care (EAPC), but also by EU projects such as the European Partnership Against Cancer.[60,84–86] In sum, these statements indicate that palliative care should be part of national cancer politics and plans.[87] How this can be accomplished in present national politics in Europe will be addressed in the following sections, where examples of different practices in organisation of palliative care in some European countries and recommendations for future politics are given.

Organisation and development of health policies and systems

Health-care systems in Europe are generally classified with respect to the role of the state, health-care providers, and payers. This triad is furthermore amended by closer or looser links with the social care sector. Countries with a strong national health service tend to have closer links between health care and other sectors, including the social care sector. Health-care systems based on social health insurance systems have a looser link with the social care sector and, consequently, more often have gaps in the comprehensiveness and continuity of care. The type of system is very relevant to palliative care, because the health and social sectors often need to interact flexibly and quickly to meet the needs of the patient and family.

Modern health-care systems in Europe build on the experiences of the 20th century, when the state's responsibility for delivery of health care became a social and political issue. This responsibility was primarily approached in three different ways: the Bismarck system,[88] the Beveridge system,[89] and the Semashko system.[90] The oldest of these systems, the social health insurance system (Bismarck system), originated in 1883.[88] The coverage was gradually extended from industrial workers to other categories of the workforce. In the 1940s, Lord Beveridge led the work on the development of the UK's National Health Service,[89] which became a more comprehensive response to the demands for full coverage, irrespective of employment status (Beveridge system). Between these two systems is the Semashko system,[90] which was developed in the 1920s by the Soviet Union to deal with the organisational aspects of health care, rather than financing or entitlements.

The main differences between the Beveridge and Bismarck systems are the degree of state control over health care and how this control is exerted. In the Beveridge system, the ministry of health is typically the budget holder and therefore commissioning services through a network of health-care providers. In the Bismarck-type systems, budgets are predominantly with health insurance companies, regulated by the ministry of health and operating in public interest. The role of the different partners has significantly more weight in Bismarck systems. Although the Beveridge system seems to perform better in terms of care coordination because health and social care are integrated in a common welfare stem, this might only be the case at the governmental level. In the Bismarck system, social and other types of care (related to health but not necessarily inherent in health care) show a large degree of fragmentation because they are financed from different sources, often as cash benefits or entitlements.

At the 2011 conference for the Organisation for Economic Co-operation and Development,[91] the sharp distinction between these two systems was described as mainly of historical interest, and the pure Bismarckian era as more or less over, because policies emphasised universal coverage rather than a right of labour. Furthermore, little, if any, scientific evidence for the superiority of one system over the other exists, specifically regarding coordination of care, for which no universal definition presently exists.[92] Palliative care has been internationally acknowledged through a resolution by the World Health Assembly.[93]

In Europe, the EAPC has, since its foundation, been scientifically, clinically, socially, and politically influential in the promotion, advocacy, and development of palliative care in Europe. In 2010, the EAPC launched the Prague charter,[84] stating that access to palliative care is a legal obligation and a human right, and thus beyond the established palliative care community. This charter was followed by the Lisbon challenge,[94] identifying four major objectives related to access to essential medicines, development of health policies that address the needs of patients with life-limiting or terminal illnesses, adequate palliative care training at undergraduate levels for health-care providers, and a structured implementation of palliative care. In 2013, the Budapest commitments presented frameworks for palliative care development as a joint initiative by EAPC, the International Association for Hospice and Palliative Care (IAHPC),[95] and the Worldwide Palliative Care Alliance (WPCA).[96] Key elements were policy, availability, education, and quality.[97]

In 2006, the European Palliative Care Research Collaborative (EPCRC) was the first palliative care research project that received funding from the European Commission under the 6th framework programme for research. The promotion and financing of palliative care research within the EU framework was a major step forward for European palliative care research. Since then, several high-quality projects on oncology and palliative care have received funding—eg, the IMPACT project, for the development and testing of quality indicators for dementia and cancer palliative care;[98] EUROIMPACT,[99] a multiprofessional research training programme; and, the International Place of Death Study.[100]

The objectives of the EU-funded PRISMA project (7th Framework Programme) were to coordinate research priorities, measurement, and practice in end-of-life care in nine countries across Europe, resulting from an

identified need for high-quality palliative and end-of-life care and research. The research agenda and subsequent guidance should reflect the European cultural diversity and be informed by public and clinical priorities.[101] Consensus was reached on the following priorities for end-of-life cancer care research in Europe: symptomatology, issues related to care of the dying, policy and organisation of services, and moving from descriptive to interventional studies.[102]

Two EU-funded projects also addressing European cancer politics have now come to an end: the European Partnership on Action Against Cancer (EPAAC)[103] and the European Guide for Quality National Cancer Control Programs (CANCON).[87] The EPAAC report on National Cancer Plans (NCPs) was based on a survey running from December, 2011, to April, 2012, in the EU Member States, Iceland, and Norway.[85] An NCP was defined as a public health programme designed to reduce the number of cancer cases and deaths, with strategies for key areas such as prevention, early detection, diagnosis, treatment, rehabilitation, palliation, and research. The survey aimed to map the current level of integration in cancer care, including palliative care, and to develop indicators to monitor the actions of NCPs across countries, before guidelines for the preparation or evaluation of cancer plans were developed.

The final EPAAC report points to significant variations in cancer control and care within and between EU Member States across the key areas of cancer care mentioned earlier. The report identified that a comprehensive approach was absent from policy documents addressing the rising needs of patients with cancer, especially because of the increasing incidence and prevalence of cancer. Finland prioritised palliative care in its national cancer plan, whereas Estonia, Greece, and Portugal were without appropriate infrastructure to carry out the NCPs adequately, especially with respect to home care and palliative care services. This means that the awareness of the need for palliative care is rising, but the political willingness to dedicate adequate resources might be lacking.

The identified inadequacies in policy mentioned earlier were included in the CANCON project, in which the primary objective was to improve overall cancer control throughout the EU.[87] The final guide covers the areas of quality-based cancer screening programmes, better integration of cancer care, community-based cancer care approaches, and survivorship.

The main target group for dissemination of CANCON deliverables were policy makers and decision makers at EU and national levels.[104] Palliative care issues were promoted as part of an overall disease trajectory, also pertaining to the primary care level.[105]

European examples of organisation of palliative care

The report by the European Parliament on Palliative Care in the European Union found a pronounced heterogeneity in the way in which national health systems care for their dying, and in the quality and access of the care provided, not only between countries, but also within them.[106] Countries involved in the CANCON project have various policies on palliative care. These policies are often nationally developed and highly influenced by local opinion leaders in palliative care; however, they do often refer to recommendations for palliative care published by international organisations, such as WHO, the EU, or the Council of Europe.[2]

	Hospitals	Outpatient clinic or day care centres	Nursing homes (and homes for the elderly)	Hospices	Home care
Belgium[107]	Y, PCU	Y	Y	N	Y
Bulgaria[108]	Y, including CCC and PCU	N	Y	Y	Y
Denmark[109]	Y, including PCU	N	Y	Y	Y
France[110]	Y, including PCU	Y	N	N	Y, including hospital at home programme
Netherlands[111]	Y	Y	Y, including PCU	Y	Y
Norway[112,113]	Y	Y	Y	N	Y
Slovenia[114,115]	Y	Y	N	Y	Y
Spain[116,117]	Y	Y	N	N	Y

Y=provider available. PCU=palliative care units. N=provider unavailable. CCC=comprehensive cancer centres.

Table 2: **Providers of palliative care in some European countries**

Policies on horizontal and vertical integration of services and structures for palliative care vary. Palliative care in Belgium, Bulgaria, Denmark, France, the Netherlands, Norway, Slovenia, and Spain is provided in various providers' organisations and across all levels of care (table 2). Hospitals are mostly either specialised cancer centres or general hospitals authorised to participate in some or all parts of oncological care. Outpatient clinics might be organised as part of departments or as special clinics for patients in need of palliative care. In many countries, nursing homes take over the care for patients who, for various reasons, are not capable of living in their homes.

In Belgium, France, the Netherlands, Norway, and Spain different types of networks and multidisciplinary teams provide coordination or care, or both, at patients' homes, outpatient clinics, and in inpatient departments in hospitals and nursing homes. The level of institutionalisation seems to depend strongly on the specific organisation of health care. Thus, in countries such as Bulgaria and Belgium, the dependence on institutional care is great; whereas, in the Netherlands, palliative care is often primarily delivered in home settings by general practitioners and specially trained nurses.

The compositions of the teams that deliver palliative care vary across European countries. In the Netherlands, a large proportion of palliative care is shouldered by general practitioners, who—among others—run inpatient palliative care units in nursing homes. On the

other hand, in many countries palliative care remains a function carried out in hospital settings or in day hospital departments as part of hospitals. The hospital-based palliative care policies are likely to become unsustainable either because of patient preferences, which indicate that patients prefer to be treated close to home when they need palliative care; or, because of the demographic changes that come with an increasing number of patients needing palliative care, which cannot realistically all be organised in hospital settings alone.

Although palliative care in European countries is delivered in different settings, it is difficult to identify a systematic pattern based on the health-care system in the country. This observation confirms the hypothesis that palliative care is underdeveloped in the health-care system, and is too dependent on individual initiatives. From the project meetings and interviews that formed part of the CANCON project, it became evident that in the Netherlands, a patient with a condition that requires only palliative or end-of-life care, or both, is discharged from inpatient oncological facility and their general practitioner and district nurse informed. Some of the patients who cannot stay and be cared for at home are placed in nursing homes with palliative care units, which are run by general practitioners trained in palliative care. In many countries, this would not meet the patient's or family's expectations. This is in contrast with the Bulgarian system, where cancer care is exclusively delivered by the so-called Comprehensive Cancer Centres, which exist in all regions.

When comparing the analyses of EU and EEA countries' cancer plans in 2011, and 2016, we observe a trend towards more frequently including palliative care as an element of the cancer plans. In most cases, palliative care is regarded as an add-on service, receiving less attention than the traditional diagnostic and therapeutic elements of cancer care.

Barriers to integration of palliative care into a comprehensive plan seem to fall into two clusters. One is the fact that health systems have different traditional and current attitudes with respect to palliative care, which impedes a more open debate on how to organise, place, and staff palliative care as an element of a continuous cancer care. The other cluster seems to be a lack of commitment from decision makers or reimbursement agencies, or both, to secure financial resources and organisation capacity that make palliative care accessible to all patients who need it irrespective of their financial ability to pay for care.

US policies on palliative cancer care

Palliative care was introduced to the USA in 1963.[118] It started as a hospice movement, focusing on the provision of home-based care to patients in the last weeks or days of life. In 1973, the first hospice was established in Connecticut. In 1978, the National Hospice Organization was founded. The Hospice Medicare Benefit Program was established by the Tax Equity and Fiscal Responsibility Act in 1982, defining the payment and policies for hospice care. By 2015, there were more than 5800 hospice programmes across the country.

By contrast with community-based hospice programmes, palliative care programmes reside in acute care facilities. The first palliative care unit in the USA was established in the Cleveland Clinic in 1988. Over time, other cancer centres have developed models of excellence for integrated palliative cancer care, such as the MD Anderson Cancer Center.[7] Since the 1990s, the proportion of cancer centres with outpatient clinics to facilitate timely palliative care has grown.[119,120] In 2006, the American Board of Medical Specialities recognised hospice and palliative medicine as a medical specialty, further promoting the growth of this discipline.

Australian policies on palliative cancer care

Palliative care has had growing recognition in Australia over the past three decades. The subspecialty was first recognised within the College of Physicians in 1988, when training also became available. Specific national policies allowing reimbursement for clinical care were introduced in 2000.

A national strategy has been endorsed by all states and territories since 2000. This strategy sought to address access and equity, models of care, and the relationship between specialist services and the rest of the health sector, including primary care. The strategy has been revised twice since its genesis, and has had comprehensive evaluations for its first two iterations.[121]

Approaches for integration of cancer and palliative care

Coordination of care, regardless of definition, is demanding, involves a vast number of professionals, and multiple transitions from one care level to another throughout the disease trajectory, which makes collaboration and integration of services paramount. One response to this complex process is the introduction of standardised care pathways, which have been adopted and adapted to cancer care in several countries (eg, Belgium, France, the Netherlands, Norway, and Spain).

Another organisational principle, focused at an even more granular level, is multidisciplinary teams. The idea of multidisciplinary teams was proposed by an EPAAC working group as a core element for an effective European cancer care policy. From this proposal, a policy statement[122] on multidisciplinary cancer care was formulated for implementation by all tumour-based multidisciplinary teams, to provide patients with the care they need. The multidisciplinary teams might be a place for integration of palliative care through an assessment of, and discussion about, patient-centred needs at any stage of the disease trajectory. The policy statement is intended to serve as a reference for policy makers and health-care providers to improve coordination.

The ASCO recommendations[123] for early referrals to specialist palliative care teams, and the other listed policy statements on integration of cancer care and palliative care, conflict with the documented workforce shortage in palliative care.[124] Thus, it is necessary to define the level of palliative care expertise at all health-care levels, be it in tertiary specialist centres or home care (see later sections of this Commission on models of palliative care integration and the role of education). Oncologists, palliative care specialists, and other relevant health-care professionals should be part of all hospital SCPs, whereas primary care workers must have basic palliative care skills to meet patients' needs. However, an Australian survey[125] reported that a substantial number of general practitioners (31%) felt they had inadequate training and insufficient resources to provide home-based care to patients with advanced cancer, which is a challenge to be addressed by educational programmes (see later section of this Commission on education).

The gap between hospital-based SCPs and the primary care level is well known, but challenging to fill because of differences in funding and administrative allocation. In practice, this gap is often compensated for by informal networks. Bainbridge and colleagues[126] explored the horizontal integration among professionals in informal palliative care networks. They found that these informal networks often produced positive results and were well accepted, but interprofessional communication and evaluative activities were commonly perceived as insufficient. Han and Rayson[127] explored the collaboration between oncological specialists and primary care doctors and their roles in the end-of-life care, and concluded that further elaboration, reflection, and research was required (panel 2).

The disease trajectory of a patient with advanced cancer consists of several subpathways, and many patients will be in an incurable state for many years, with large variations in the need for palliative care. During these years, several transitions of life expectancy will occur, all of which present multiple challenges and complaints related to insufficient communication across care levels, fragmented care, and unclear responsibilities. Thus, we recommend that assessment of patient preferences and planning of transitions should be focused in early palliative care consultations, as should the use of SDM as part of the SCPs. This seems pertinent, given that 82% of late palliative care (<90 days before death), as reported in a study by Scibetta and colleagues,[128] was for end-of-life admission to hospital, or that only 8% of patients with lung cancer in the USA see a palliative care specialist, often to address end-of-life issues.[129] As a rule, a patient's needs should be assessed as a continuous process from diagnosis onwards, and palliative care needs should not be an exception to this rule.

The work in the CANCON project, therefore, did not focus on one particular aspect of cancer care in isolation, but rather on defining, or redefining, the care pathways of patients with cancer to map all services required to meet patients' needs throughout the disease trajectory and beyond. This means that cancer patients and in particular, cancer survivors, need support and management of their health issues and challenges beyond the curative phase. Such efforts will often involve their families and other sectors of the society. A 2018 Canadian study[130] showed that citizens' expectations are high with respect to the integration of palliative care standards into the Canada Health Act, and thus into the basic processes of care. The survey showed that there are clear concerns around the financial accessibility of such care, but this is regarded as a condition for successful implementation of such a programme. The majority of Canadians agree that surveys should be done among family members (84%), caregivers (82%), and patients (79%) regarding the care received, and 72% of Canadians agree that annual surveys should be done to measure and track Canadians' level of awareness of palliative care.[130] At the political level, these findings support the obligation for politicians and health authorities to put palliative care on the agenda as an integrated part of the health-care system, and not as a so-called hidden service for dying patients.

***Panel 2:* Requirements for collaboration between oncological specialists and primary care doctors**

- Definition of when end-of-life care begins
- Assessments of the patterns and specific components of end-of-life care as provided by different types of oncologists and primary care physicians
- Understanding of patient and caregiver preferences for the relative involvement of oncology versus primary care medical specialists at the end of life
- Design of appropriate and validated assessment tools to further understand how end-of-life care should best be managed
- Evaluation of the effect, in terms of quality of care and other endpoints, of different models of end-of-life care and understand how these different models might be implemented in different health-care delivery systems
- Ascertainment of best practices and methodologies for the integration of primary and oncology specialty care in patients dying of advanced cancer

Costs and cost-effectiveness of palliative care

Major concerns in oncology today are the rapidly increasing complexity of treatment and costs of care, which threaten the sustainability of the present services.[22,131] As pointed out by Isenberg and colleagues,[123] increased delivery of palliative care, as recommended by the updated ASCO guidelines,[15] must be accompanied by changes in the financing of health care.

An editorial in the *Journal of Oncology Practice*[132] concludes that the determination of cost-effective

methods to care for patients with advanced cancer should be given high priority, based on the rapidly increasing demand for palliative care in an ageing population. However, valid methods for cost estimates that consider both cost-effectiveness and cost-benefit analyses (outcomes translated to money) need to be established. Although palliative care interventions have been shown to improve patient-reported outcomes[3,5,56,133–136] and cut costs for second party payers and hospitals,[137–139] most studies are small and are done from the health services perspective, not the societal perspective.[132] Thus, they often do not include patient, caregiver, and societal costs in the calculations.

Intensive end-of-life care is expensive, but studies fully illuminating the costs associated with integration of oncology and palliative care are in short supply. There are findings that indicate integration is more cost-effective than standard treatment. Early palliative referrals improve end-of-life care in terms of earlier hospice referrals,[140,141] lower readmission rates to hospitals,[142] and shorter length of hospital stay,[143] contributing to substantial reductions in cost. According to Cassel and colleagues,[144] early palliative care is an excellent example of how to improve or maintain quality of health-care delivery for patients and caregivers at a lower cost. Furthermore, most costs in late-stage cancer have been shown to result from advanced therapy with marginal effects, intensive care unit and emergency admissions, and protracted hospital stays, rather than from direct personnel costs.[145] Estimates from the USA and UK indicate 25% of health-care expenditure is related to patients in their last year of life, whereas end-of-life care takes up 20% of hospital beds.[146,147] In sum, these figures and findings indicate expenditures that can be reduced, and that integration can serve this function.

The present evidence of better care at lower costs associated with early access to palliative care makes it necessary to evaluate the policy on subsidies, revenues, payment for patients, reimbursement practice, and organisation of services to promote integration of oncology and palliative care. Although copayment for patients might be one option to promote integration, it might be unacceptable from a societal point of view because underserved populations might refrain from using the service. Compulsory palliative care consultations alongside tumour-directed treatment at a certain stage of advanced disease is another option; however, use of a time-based model, as compared with a patient-centric, need-based model,[148] adds cost to the already substantial cost to this group of patients. This added cost primarily relates to personnel costs at the tertiary level; eg, consultations with both oncologists and palliative care specialists, and more time allocated to the consultations. Another option is to make reimbursement conditional on palliative care involvement at a certain stage in the disease trajectory.[123]

Larger and sufficiently powered cost studies showing that these additional costs offset savings in other domains of oncology and end-of-life care are needed. Greer and colleagues[149] analysed cost data from Temel and colleagues' study,[3] and found that patients in the early palliative care group had higher hospice costs, but lower costs related to chemotherapy in the last 30 days of life than patients in the control group. Some studies have examined the cost-effectiveness of specialised palliative care, and report diverging results. This divergence is mainly related to differences in financial incentives and reimbursement issues, whether patients are seen exclusively on an outpatient basis, if the unit is located together with other highly specialised teams providing palliative care services, and referral and follow-up practice. Referral and follow-up practices will be an important and political issue in the years to come, as an increasing amount of palliative care must be delivered by primary health-care services. As pointed out previously, the need for care delivery at this level has implications for the education of primary health-care personnel (see the section of this Commission on the role of education). Systematic palliative care interventions initiated at the specialist levels, but also followed by multidisciplinary palliative care teams, have improved patient-reported outcomes and proven cost-effective.[150–152] The 2017 book by Gómez-Batiste and Connor[153] states in its general conclusion, based on global data, that home and community-based services are emphasised over building inpatient palliative services.

Researchers have started examining a quantifiable, or at least a qualitatively comparable, contribution of the different models in palliative care. An example of such a study is that by Siouta and colleagues[154] from 2016; the authors did a qualitative systematic literature review of empirically tested models in cancer and other chronic diseases, including 14 studies, seven models for chronic disease, four for integrated care in oncology, two for both cancer and chronic disease, and two for end-of-life pathways. The involvement of a palliative care multidisciplinary team resulted in better symptom control, less caregiver burden, improvement in continuity and coordination of care, fewer admissions to hospital, cost-effectiveness, and more patients dying in their preferred place. The authors proposed a generic framework for integrated palliative care in cancer and chronic disease. This framework promotes the integration of palliative care in the disease trajectory concurrently with disease-oriented treatment, and the employment of a palliative care-trained multidisciplinary team with a three-fold focus: treatment, consulting, and training.

Few resources, pressures on cost containment, cost-effectiveness, and overall cost control are present in cancer care, as well as in palliative care; consequently, it is necessary to look at the best performing types of care in the whole cancer care trajectory. Smith and colleagues[137] did a comprehensive review of available international evidence on the cost and cost-effectiveness of palliative

care in any setting (hospital based, home care, or hospice based). The quality of retrieved papers was assessed against 31 indicators developed for the purpose of their review. The authors identified 46 papers meeting the inclusion criteria; from these they found that palliative care is very often less costly relative to the comparator groups and, in most cases, the difference was statistically significant.

Standards, guidelines, and guidance are meant to standardise procedures, and SCPs can be used as an implementation tool to equalise quality and enable comparative analysis in health care. As much as SCPs are helpful, at the political level they might cause tension and frustration related to struggles to secure adequate human and financial resources. However, if a country's goal is to deliver high-quality cancer care, these tensions and frustrations need to be addressed, and directions need to be given by the governments based on a sustainable health policy and independent of who is in power. This approach is strongly supported by all international statements that access to palliative care is a human right.

Given the challenges facing patients, care providers, and the system as a whole, the bulk of financing should come from public funds, or, at least, the share of public financing dedicated to palliative care should not be different from the financing of other health-care services within a given system. To raise the profile of palliative care at the political level, the following arguments could be made: (1) the needs for palliative care are rising, and many present needs are unmet; (2) palliative care is part of the cancer care continuum; (3) palliative care is patient centred and should be delivered systematically; (4) SCPs can secure availability of palliative care, but presupposes relevant professionalism at all levels, and willingness and resources for the implementation; (5) the population is fragile, does not demand expensive treatments, but is without public representatives; (6) the industry or other key stakeholders with easy access to the political decision-making processes are focused on treatments other than palliative care; and (7) the fragility of both patients in need of palliative care and their relatives incapacitates them in the public debate on resource allocation, and public funding is therefore necessary. The main question is: how can we ensure policies on palliative care are effectively implemented? Concerted action of cancer care professionals and patients, through advocacy efforts, is needed; specifically, a case needs to be made for the currently unmet needs that place a significant burden on the individual, family, health care, and, ultimately, on society as a whole (panel 3).

Societal challenges

Despite the growing evidence for the benefits of integration of palliative care and oncology for patients and those close to them and to health-care systems, many challenges remain. Some of the challenges can be considered societal; ie, problems in the interactions and structures within society and the normal patterns of practice. Societies are comprised of many different communities, in turn comprised of many different groups of people; any issues associated with these groups can be described as societal. In this section, we consider the challenges at societal, professional, patient, public, media, and medical education levels that could hamper the better integration of palliative care and oncology.

Professional: oncologists, palliative care, surgeons, general medicine, and primary care

Although much practice by oncologists involves people with advanced cancer, and despite recommendations by ESMO[155,156] and the Organisation of European Cancer Institutes[157] that, to be designated, a cancer centre must have integrated oncology and palliative care, the liaison and integration of oncology with palliative care varies considerably.

A survey[158] of 895 members of ESMO from 64 countries, including 34 in Europe, regarding their involvement in and attitudes toward the palliative care of patients with advanced cancer, found that although the importance of

***Panel 3*: Policy—recommendations**

Barriers

- Palliative care not perceived as a needed integral part of the cancer care continuum
- Deficient planning of palliative care at national and regional levels
- Insufficient organisational and infrastructural capacity of palliative care
- Palliative care limited to respite care and supportive care, and often left to the family
- Inadequate assessment of costs and benefits of palliative care

Solutions

- Establishment of standardised care pathways that cover all cancer care services (envisaged also by National Cancer Control Programs)
- Adherence to the European Guide for Quality of National Cancer Control Programs
- The need to invest in palliative care infrastructure—partly related to the workforce
- Build on infrastructure for palliative care also in outpatient and home settings to address the needs of cancer patients
- Transparency of direct and indirect costs, and also doing health technology assessment for palliative care procedures

Recommendations for immediate action

In order to develop better integration of oncology and palliative care, WHO and professional organisations (European Association of Palliative Care [EAPC], Worldwide Palliative Care Alliance [WPCA], International Association for Hospice and Palliative Care [IAHPC], European Oncology Nursing Society [EONS], European Society for Radiotherapy and Oncology [ESTRO] and American Society of Clinical Oncology [ASCO], among others) should work together to establish consensus on structure and implementation plans to guide policy makers based on present best knowledge for the following areas:

- Convergent policies worldwide addressing integration of oncology and palliative care
- Organisational structures of early integration of oncology and palliative care in hospitals
- Organisational structure of early integration and collaboration between hospitals and community care in oncology or palliative care, or both, at global level need to be developed

palliative care was recognised, actual participation levels are suboptimal. 43% of respondents reported that they directly administered end-of-life care often, and 74% reported that they derived satisfaction from their involvement in end-of-life care. Only around a third of respondents often collaborated with a palliative care specialist (35%), a palliative home care service (38%), an inpatient hospice (26%), or a psychologist (33%). Yet, respondents were more commonly involved in treating physical symptoms (eg, pain [93%], fatigue [84%], and nausea or emesis, or both [84%]), than in managing psychological symptoms and end-of-life care issues (eg, depression or anxiety, or both [65%], existential distress [29%], or delirium [12%]). Most respondents (88%) endorsed the belief that medical oncologists should coordinate the end-of-life care for their patients with cancer, but almost half (42%) said they felt they were trained inadequately for this task. Although most of the responding medical oncologists expressed positive views regarding their involvement in the palliative care of patients with advanced cancer and patients who were dying, 15% of respondents had pervasively negative views.[158] Similar challenges have been reported among oncologists in other countries, including China, Thailand, USA, and many others.[159–169]

Oncologists' end-of-life care attitudes can influence their timely palliative care referral and end-of-life cancer treatment decisions. Oncologists often refer patients to palliative care late in the course of illness,[163,164,170–173] despite believing—as found in recent surveys[170,173]—that integration of early specialist palliative care in cancer improves symptom control, end-of-life care, health-related communication, and continuity of care. A survey[174] of 182 oncologists from a major cancer centre in the USA found that comfort with the concepts of end-of-life care was associated with higher rates of specialist palliative care referral and self-reported primary palliative care delivery. A 2015 systematic review[52] found that the definitions of the concepts of integration varied.

In many instances, decisions against intensive treatments are often made only when death is imminent. A study[175] in which Belgian oncologists were interviewed identified seven categories of barriers that discouraged oncologists from discussing palliative care: oncologist-related; patient-related; family-related; barriers relating to the physician referring the patient to the medical oncologist; barriers relating to disease or treatment; institutional or organisational barriers, or both; and societal or policy barriers, or both. Communication, approaches to the management of uncertainty in illness, and broader cultures and the focus of research in oncology might play a role here. Sympathetic, yet honest, communication about the irreversible nature of advanced cancer is important to improve patients' prognostic understanding and, thereby, to allow for treatment intensity to be adjusted to realistic goals, and to overcome some of the patient-related and family-related barriers. A qualitative in-depth interview study[176] in Germany found that oncologists reported patients with unrealistic expectations to be a challenge for end-of-life communication, especially in comprehensive cancer centres. Oncologists responded to this challenge quite differently, by either proactively trying to facilitate advance care planning or passively leaving the initiative to address preferences for care at the end of life to the patient. A major impediment to the proactive approach was uncertainty about the right timing for end-of-life discussions, and about balancing the medical evidence against the physician's own subjective emotional involvement and the patient's wishes. These findings might help to explain why end-of-life communication is often started rather late with patients with cancer.

Uncertainty in prognosis and likely treatment outcomes is inevitable in complex illnesses with evolving treatments, like cancer. In modern times, with increasingly intensive treatments and population ageing, more people face more complex treatment, care decisions, and uncertainty.[177] Uncertainty can become a major barrier to effective care because clinicians delay raising issues or making decisions in an attempt to reassure in the face of uncertainty.[178] A study[177] of decision-making processes during critical care found that decisions were made serially, over the whole disease trajectory, which usually covered several days or weeks. Four trajectories with distinct patterns were identified: curative care from admission; oscillating curative and comfort care; shift to comfort care; and comfort care from admission. Conflict between patients and clinical teams and within clinical teams occurred most commonly in the trajectories with oscillating curative and comfort care. This complex web of discussions means early communication is needed, especially around the values and preferred care outcomes from care of patients and their families. The study also suggested there should be clearer discussions of treatment plans, rather than waiting until the end of life.

A further issue impeding integration might be the research focus of oncology versus that in palliative care. Only a tiny proportion of research spending in cancer is allocated to palliative or end-of-life care, by contrast with that spent on studying oncological treatment. Data on research funding by National Cancer Research Institute partners in the UK, based on studies included in the National Cancer Research Database for 2015–16, found that, of the £579·79 million awarded for research into cancer, just 0·33% (£1 925 909) was allocated to palliative and end-of-life care. By contrast, £207·28 million (36%) was allocated to research into treatment, and £163·11 million (28%) to research into the biology of cancer.[179] This small amount is often spent across multiple projects, meaning that the support for evaluative trials, or new palliative treatments, is insufficient.

These figures are similar to those reported for 2010, when only 0·24% of cancer research spending in the UK

went to palliative or end-of-life care, although the overall funding for research in cancer increased slightly.[180] Similarly, in the USA, of the National Cancer Institute's total appropriation for 2010 of US$5 billion, only 1% was awarded to palliative care research.[180] Data in Australia mirror these findings, although, on a positive note, the Australasian Clinical Oncology Research Development programme specifically seeks to attract young clinical palliative care researchers to develop their clinical trial protocols alongside young oncology trainees. This focus on research on treatment might further drive oncologists towards tumour-directed treatment and in valuing cure over improving quality of life and palliative care. Opportunities for oncologists to develop in teaching hospitals, with a combined career in research and practice, are therefore almost exclusively in the area of cancer biology or cancer treatments and almost never in palliative care, where the funding for individual projects seems to be insufficient to support a substantial fellowship for a PhD or MD. Investment in research into palliative and end-of-life care is urgently required to inform the transition from tumour-directed care to palliative care, improve symptom control, deliver cost effective care, and ensure that choices at the end of life are offered and met; in turn, this will help to further the integration of palliative and oncological care.

There are some proposals that palliative care would be more acceptable to oncologists if it were renamed supportive care.[181,182] However, others have argued that any proposed renaming clouds the more nuanced issues, such as attitudes and resources, and the issues raised earlier, which together hamper referrals.[183] Supportive care is something that all oncologists should do, and the term is much linked to cancer. Others have proposed renaming palliative care as enhanced supportive care. The important questions, however, should be around what patients and families feel are appropriate services, not what professionals feel they would like to refer to when discussing their service.

A further consideration is the attitudes of palliative care to oncology. Palliative care services are overstretched, with staff shortages and insufficient resources to treat all patients. They are often supported by the charitable sector, and, in many countries, are not included in mainstream health-care funding. These factors can lead to services being limiting. The US hospice benefit, which reimbursed the provision of hospice care under Medicare, included the stipulation that patients should have a prognosis of 6 months or less, and that patients in hospices should agree to withdraw from all treatment of potential curative intent.[184] Although this definition does not exist in most countries outside the USA, the earlier focus on palliative care at the end of life can limit referrals. Palliative and oncology clinicians have to recognise the change in the needs of patients with cancer; specifically, the need for earlier, more integrated care as a consequence of changes in treatment and disease trajectory. This was clearly expressed at the 67th World Health Assembly, when WHO passed the first resolution on palliative care, recommending national health systems provide palliative care in conjunction with potentially curative treatment, and not just as an optional extra.[185] The resolution urged Member States to develop and implement policies that support the integration of cost-effective and equitable palliative care services in the continuum of care, across all levels.[186] A modern approach to palliative care can also include an integration with oncology and relevant community and hospital services.[187]

Patients, families, the public, and the role of the media

Public priorities when faced with a terminal illness, such as an advanced cancer, would suggest that better integration of oncology and palliative care is important for care and would be preferred. A population-based survey[188] of people's priorities for treatment, care, and information across seven European countries asked respondents for their priorities if faced with a serious illness, like cancer, with limited time to live. Of the 9344 individuals interviewed, most people (57% [Italy] to 81% [Spain]) would choose to improve quality of life for the time they had left. Only 2% (England) to 6% (Flanders) said extending life was most important. An important minority (15% [Spain] to 40% [Italy]) said quality and extension were equally important. Prioritisation of quality of life was associated with higher education in all countries. The survey included people with different health statuses, but these did not affect priorities. Further components of this survey in the open-ended questions identified a public perception of needs for improved quality of end-of-life and palliative care and access to this care for patients and families, and a recognition of the importance of death and dying, the cessation of treatments to extend life unnecessarily, and the need for holistic care to include comfort and support.[189] Most people would want to know if they had a terminal illness, and factors associated with this wish have been identified.[190]

Public awareness of palliative care and related services among oncology patients is often scarce. One survey,[191] done in London, UK, found that only 19% of patients recognised the term palliative care, although 68% understood the role of the hospice, and 67% understood the role of Macmillan nurses (specialist nurses providing an advisory palliative care service in the UK). Age-adjusted multiple logistic regression found that the most socially and materially affluent patients were eight times more likely to recognise the term palliative care, compared with those who were the poorest. A survey[192] in Japan found similar challenges in awareness of palliative care. In 2017, an internet search query[193] in the USA found that public awareness of the term palliative care is growing month by month.

Uncertainty around decision making and difficulty with communication are also likely to have a role in hampering

the integration of palliative and oncology care for patients with cancer during treatment. In a qualitative study[177] of intensive care, uncertainty was a pervading feature over the trajectory of care. Families were most often involved in decision making regarding care outcomes, and seemed to find it easier when patients switched definitively from curative to comfort care. Some families considered decision making a negative concept, and preferred uncertainty. We found eight categories of decision making: three related to the care outcomes (aim, place, and response to needs) and five to the care processes (resuscitation, decision support, medications/fluids, monitoring/interventions, and other specialty involvement). The study suggests a need to support early communication, especially around values and preferred care outcomes, from which other decisions follow, including "do not attempt to resuscitate" decisions. Simple tools to understand patients' and families' priorities and aid communication have been developed and undergone preliminary testing, with many promising to improve this situation.[194]

Stigma surrounding cancer is common, and presents a great challenge to treatment and care,[195–197] including to palliative care and its integration with oncology. Stigma can have a silencing effect. The social, emotional, and financial devastation that all too often accompanies a diagnosis of cancer is, in large part, due to the cultural myths and taboos surrounding the disease.[195–197] There are several reasons that cancer and, within this, palliative care might be stigmatised.[198,199] Symptoms or body parts affected by cancer can cultivate stigma, as can beliefs about treatment.[200] Pain, other symptoms, or the cancer itself can be seen as a test or punishment, affecting the willingness to use therapies or to be referred to palliative care.[201] Breathlessness and cough are common symptoms, but are associated with social withdrawal, non-response of services, and invisibility.[202,203] Depression is a stigmatising symptom in many countries.[204] Negative illness perceptions can increase depression.[205] Some cancers or their treatment cause changes in appearance, which can also be distressing and result in stigma.[206] Fear of dying and the stigma associated with terminal events might also hamper access to palliative care.[207] Although many people report that they grow despite cancer, treatment, and through stigma, appropriate support systems and resilience are needed.[206]

News reports about cancer frequently discuss intensive treatment and survival, but rarely treatment failure, adverse events, end-of-life care, or death.[208,209] These portrayals of cancer care might give patients an inappropriately optimistic view of cancer treatment, outcomes, and prognosis. Language in the media likening cancer to a battle or war and conflating cancer and fear[210] might lead people whose disease is continuing despite treatment to feel like a failure (ie, that they are losing the war) and become reluctant to seek or discuss any alternative. All of these factors might result in difficulty in communication, and create stigma associated with accepting anything not directed towards cure.

Public communication is probably crucial to decrease cancer-related and palliative care-related stigma, raise awareness, disseminate education, and direct patient and family care.[211,212] Wide-ranging public education; links to schools; use of modern forms of media, such as social media; use of web-based media for better information about cancer care and palliative care;[213] and more traditional health education are needed.[214] Cultural differences in beliefs in, and response to, cancer, palliative care, information needs, and end-of-life care need to be respected and accounted for in this communication process.[215]

Despite the fact that cancer is a major and increasing health problem, particularly in older people, paradoxically, older people with cancer are often undertreated when compared with younger patients, and are excluded from clinical trials.[216] The inequalities do not only pervade new therapies, but also reconstruction surgery, nursing, primary, and palliative care—eg, immunotherapy, breast reconstruction, and chemotherapy rates are lower for older patients than for younger patients. In one study,[217] nurses' visions of ageing influenced reduced support for breast reconstruction: nurses with a negative view of age discriminated against a 75-year-old patient more than a 35-year-old patient (ie, less encouragement was given to the older patient). Older patients have less access to inpatient hospice and palliative care services than younger patients, although this seems to be improving slightly.[218] Older people are more likely to die in hospital and less likely to die at home, which is often their preferred place of death, when compared with younger patients.[219] A large population-based study[220] found that older patients with lung cancer (aged >60 years) had significantly lower chances of receiving opioids than their younger (aged <50 years) peers (prevalence ratio range, 0·14–0·78), even adjusted for comorbidity.

Barriers and challenges related to death and dying

Death and dying are often taboo subjects associated with considerable stigma for people who are dying and those close to them. This is a challenge at a professional level, patient and caregiver level, and a societal level. A study[221] of 233 college students used a range of semantic differential adjectives to explore their attitudes toward young and old people who were healthy, ill, or terminally ill. The results identified negative attitudes toward dying people in both young and old age groups; their role was conceptualised as undervalued, indicating stigma towards those who are terminally ill. Saunders[222] wrote on the need to change this stigma, and focus on living and dying well. Writing in *The Lancet* in 1984, Wilkes[223] drew attention to the challenges that such stigma brings.

Stigma and taboo still pervade society, leading some countries to launch education campaigns in response—

eg, the UK's Dying Matters initiative.[224] Because death has become less common in our daily lives, it has possibly become harder to consider our own mortality, or that of those close to us. Some researchers and clinicians have said that there is neglect within oncology with regards to patients who are dying. This might be a particular problem in oncology, and sometimes in cancer nursing, where the focus is on more treatment, on cure, and on fighting the illness, rather than on living and dying well.[225] The emphasis on cure might be helpful when encouraging patients to come forward for screening or early treatment,[226,227] but there are many examples of patients receiving chemotherapy in the last 30 days of life, when it is not thought to be effective.[228] Death often remains a taboo subject in the clinical encounter.[229] An absence of openness about death has negative consequences for the quality of care provided to the dying and bereaved, with missed opportunities for symptom management and psychosocial support.[222] Lack of honest disclosure is seen along the disease trajectory, from time of primary diagnosis to relapse and terminal illness. This prevents patients and families to reorganise and adapt their lives to the present situation.[230]

An absence of openness often pervades undergraduate and postgraduate medical education, including specialist training in oncology, in which many doctors and students feel unprepared to discuss death and dying, deteriorating illness or even to break the news of a death to family members and friends.[231,232] Failure to have those conversations can deny patients and families the opportunity to make important decisions.[230] These are difficult conversations; some might not want to talk about the end of their life, and others might want to talk, but at different times and stages. It is often difficult to know how to open these conversations, but there is evidence that through training and continued support it can be done, even in the context of offering further treatment.[233–235] Tools have been developed to help clinicians to ask about and understand patient priorities, and these could be a starting point for dialogue.[194]

Implications

Cancer is one of the most common health issues in society. Worldwide, 14·1 million new cases and 8·2 million deaths from cancer were reported in 2012. The most commonly diagnosed cancers were lung cancer (1·82 million), breast cancer (1·67 million), and colorectal cancer (1·36 million); the most common causes of cancer death were lung cancer (1·6 million deaths), liver cancer (745 000 deaths), and stomach cancer (723 000 deaths).[236] The Global Burden of cancer analysis from 2008, showed that an estimated 169·3 million years of healthy life were lost to cancer that year.[237] Colorectal, lung, breast, and prostate cancers are the main contributors to total years of life lost in most world regions, and caused 18–50% of the total cancer burden.[237] Cancer will increase in all parts of the globe. Currently, around 44% of cancer cases and 53% of cancer deaths occur in countries at a low or medium level of the Human Development Index.[236] Projections suggest that if the cancer-specific and sex-specific trends estimated in this study[237] continue, the incidence of all cancer cases will increase from 12·7 million new cases in 2008 to 22·2 million by 2030.[238] This affects all countries, with an increase of 68% compared with 2012 overall, and 66% in low and medium Human Development Index countries and 56% in high and very high Human Development Index countries.[238]

Although early resolutions regarding palliative care mainly focused on the more advanced stages of disease and the end of life,[29] the WHO mandate on palliative care has been extended to include patients in the early phase of all diseases. This evolution of the WHO mandate reflects the evolution of the concept of palliative care as a whole,[239] which consists of extension of care beyond cancer and into more general chronic conditions, promotion of early palliative interventions in the clinical evolution of the disease, application of palliative care measures in all settings of the health-care system, and identification of complexity versus prognosis as criteria for specialist interventions. In other words, the focus of palliative care has shifted from the concept of terminal illness to advanced chronic illness with a limited prognosis, and from a specialty approach to a national health-care system approach.[29,240] Recommendations are presented in panel 4.

Prognostication

The importance of prognosticating in oncology and palliative care

Prognostication is the skill of predicting future outcomes. The outcome that is most commonly predicted is the duration of patient survival, although one can also prognosticate about other clinically relevant outcomes, such as symptomatic response to palliative treatment, discharge from hospital, or recovery of function. Once

Panel 4: **Societal challenges—recommendations**

- Encourage public actions that focus on death as a part of being human by developing international and national consensus programmes (campaigns) on being mortal; and engaging in the international and national parliaments, patient organisations, and professional organisation campaigns
- Destigmatise palliative care by developing international and national consensus programmes and engaging parliaments, patient organisations, and professional organisations in the campaigns
- Ensure economic resources to palliative care and palliative care research reflect the needs and the volume of the patients in oncology practice by establishing an international expert panel to develop multinational estimations of needs, reflecting the complexity of the patient population
- Raise public awareness of the goals of tumour-directed treatment (life-prolonging, symptomatic, and end-of-life care) by starting international and national discussions on information policies and communication in the public domains aiming to raise awareness of the marketing by the medical industry and health-care providers

patients have received an accurate diagnosis of cancer, the next question is frequently about the likely prognosis.[241]

Oncologists are routinely required to prognosticate. At diagnosis, prognostication primarily relies on an accurate staging of the extent of disease. All cancer staging systems are based on the premise that the severity and extent of disease is associated with different outcomes (particularly the risk of death). At diagnosis, the stage of disease frequently dictates the preferred course of treatment. Detailed prognostic information about survival associated with each stage of disease can help patients and clinicians to make informed decisions about the best course of treatment.

In palliative care practice, the issue of prognosis is also very important, although, in these circumstances, the question is more specifically about how long patients are expected to live, rather than on predicting their response to further treatment.[242] In routine practice, issues of prognosis are pertinent to decisions and discussions about place of care, advance care planning, and determining ceilings of care.[243–245]

At the interface of oncology and palliative care, prognostic questions are most relevant to the decision about whether or not to proceed with palliative chemotherapy. Deaths occurring within 30 days of chemotherapy are increasingly recognised as an indicator of the quality of oncological care.[246] When used appropriately, palliative chemotherapy can improve quality of life and survival in patients with advanced cancer;[247] however, when given to patients who are near the end of life, even to those with a relatively good performance status, chemotherapy seldom has benefits, and might adversely affect the quality of death.[248] Early involvement of palliative care services can reduce the frequency of chemotherapy administration close to death, without any adverse consequences for survival.[3,249] In 2008, the UK National Confidential Enquiry into Patient Outcome and Death[250] reviewed deaths occurring within 30 days of systemic anticancer chemotherapy treatment (SACT). External review suggested that the decision to give palliative SACT was inappropriate in 19% of cases (because of factors such as poor performance status, lack of realistic prospect of benefit, or end-stage disease). In 27% of patients receiving palliative chemotherapy, external advisers considered that the treatment might actually have caused or hastened the patient's death. The authors recommended that, before administering SACT, oncologists should fully discuss the aims and likely outcomes of treatment with patients, including a discussion of the option of no treatment. Moreover, for patients with an ECOG performance status of 3 or 4, the authors recommended that palliative chemotherapy should only be embarked on with caution and after consideration by a multidisciplinary team.

Discordance between patients' and clinicians' perceptions about the intended purpose of chemotherapy is common.[251–253] In one study,[253] only 108 of 216 patients correctly identified whether the treatment they were receiving was curative or palliative in intent. Similarly, in another study,[254] 64% of patients with incurable lung cancer did not report understanding that their radiotherapy was unlikely to cure them. This mismatch between clinicians' and patients' understanding about the indications for their treatment is not confined to oncologists. In a 2015 study,[255] 57·4% of patients with metastatic lung, and 79·8% of patients with metastatic colorectal cancer believed that their surgery was likely to have been curative. Moreover, evidence exists that patients with advanced cancer are subject to increasing numbers of radiological investigations,[256] and to a higher frequency of investigations when they are closer to death, and of artificial nutritional support, even in the context of decreased SACT.[257]

Predicting survival in advanced cancer using prognostic tools

Accurate staging can provide valuable prognostic information, guide decision making about treatments at the individual patient level, allow for a common international terminology so that different centres can accurately describe the case-mix of their patients and compare outcomes, and is essential for the identification of homogeneous populations for entry into clinical trials.[258] However, in the context of palliative care, when nearly all patients have metastatic disease, the usefulness of current staging systems is more restricted. In advanced disease, traditional prognostic factors (eg, site of primary cancer, and number and sites of metastases) might be less relevant because many patients with advanced cancer follow a common disease trajectory of increasing debility, anorexia, cachexia, fatigue, and decreased mobility. This trajectory, in many cases, ultimately leads to confusion, drowsiness, coma, and death.[259] In these circumstances, simply knowing that a patient has stage IV disease does not help to distinguish between patients with prognoses of days, weeks, months, or years. Clinicians frequently rely on their own clinical judgment or intuition to arrive at prognostic estimates. However, systematic reviews consistently show that such estimates are often inaccurate and overly optimistic.[260,261]

The most commonly used qualitative method for the prediction of survival in patients with advanced disease is the so-called surprise question. The surprise question ("Would you be surprised if this patient died within the next X months?"), used either alone or as part of the Gold Standard Framework proactive identification guidance tool,[262] has been recommended as a way to identify patients who might benefit from referral to specialist palliative care services. A 2017 systematic review[263] reported that, overall, the surprise question was accurate on 74·8% of occasions. Although the positive predictive value of the surprise question was low (30%), it performed better at screening out those patients who were not

expected to die within a specified timeframe (negative predictive value 90%).

In response to the inaccuracy of clinicians' predictions, an increasing number of prognostic tools have been developed specifically for use in patients with advanced cancer.[242,264–266] There is no consensus about the most accurate or practical tool for clinical use; however, a few of the better validated tools are shown in table 3, and are discussed below.

The Palliative Prognostic (PaP) score[267,268] consists of six variables. Partial scores are allocated to each variable and the total score determines whether the patient is at high, intermediate, or low risk of death within 30 days. The PaP score has been externally validated in several studies,[265] and the original performance of the tool has been broadly replicated. The total PaP score is more accurate than a simple clinician prediction of survival and, somewhat paradoxically, its accuracy might be improved by removing the clinician prediction of survival from the scoring algorithm.[277] A modified version of the PaP score (including delirium as an additional prognostic factor), the D-PAP, has also been developed,[269] and is more accurate than the original. One criticism of both the PaP and D-PaP scores is that they are heavily reliant on a clinician prediction of survival to generate the overall score. The Palliative Performance Scale (PPS)[270] was developed as a modification of the Karnofsky Performance Status,[278] with a focus on patients with poorer mobility or self-care abilities, or both, and the inclusion of other potentially relevant prognostic indicators. A 2017 systematic review[265] reported that the scale had been evaluated in 18 studies (n=21082) in numerous countries and multiple tumour types. In these studies, the PPS can distinguish between patients with differing survival outcomes.[279,280] Prognostic accuracy has not been directly compared with clinician pre-dictions of survival. The Palliative Prognostic Index (PPI)[271] is calculated using five clinical variables. The model stratifies patients into three groups: survival of less than 3 weeks, less than 6 weeks, or more than 6 weeks. PPI has been validated in several studies,[281,282] and it has the advantage of relying neither on the clinician prediction of survival nor on laboratory measures (which can be challenging to obtain in palliative care patients). Prognostic accuracy improves if used between 3 and 5 days after admission to a palliative care unit, rather than on admission.[283] It is more accurate than clinician predictions of 30-day survival, but not 100-day survival.[284] Perhaps the simplest measure is the modified Glasgow Prognostic Score (mGPS),[272–274] which is calculated from the amount of serum C-reactive protein and albumin. The mGPS is used to distinguish patients with good, intermediate, and poor prognoses.[265,285] The scale is simple to calculate, and has been widely used in various cancer types. Its prognostic value is based on its association with the severity of the cachexia syndrome.[286] Feliu and colleagues[275] developed a prognostic nomogram consisting of five variables (ECOG performance status, serum albumin, lactate dehydrogenase, lymphocyte counts, and time from initial diagnosis to diagnosis of terminal disease) to predict survival at 15, 30, and 60 days. In 2011, Gwilliam and colleagues[276] reported the development of the Prognosis in Palliative care Predictor

	Variables included in score	Type of prognostic estimate
Palliative Prognostic Score (PaP)[267,268]	Dyspnoea; anorexia; Karnofsky performance status; total white cell count; lymphocyte percentage and clinician prediction of survival	Scores divide patients into three risk groups: (A) >70% probability of surviving 30 days; (B) 30–70% probability of surviving 30 days; and (C) <30% probability of surviving 30 days
Delirium PaP (D-PaP)[269]	Delirium; dyspnoea; anorexia; Karnofsky performance status; total white cell count; lymphocyte percentage; and clinician prediction of survival	Scores divide patients into three risk groups: (A) >70% probability of surviving 30 days; (B) 30–70% probability of surviving 30 days; and (C) <30% probability of surviving 30 days
Palliative Performance Scale (PPS)[270]	Ambulation; physical activity and extent of disease; self-care abilities; oral intake; conscious level	Patients can be divided into risk groups according to PPS score of 10–100%; life tables can be used to predict probability of surviving to defined time periods
Palliative Prognostic Index (PPI)[271]	PPS score; oral intake; dyspnoea; oedema and delirium	Patients are stratified into three groups: survival shorter than 3 weeks; shorter than 6 weeks; or >6 weeks
Modified Glasgow Prognostic Score (mGPS)[272–274]	Serum C-reactive protein and albumin	Patients are stratified into three groups: good, intermediate, and poor prognosis
Feliu Prognostic Nomogram (FPN)[275]	Eastern Cooperative Oncology Group performance status; serum albumin; lactate dehydrogenase; lymphocyte count and time from initial diagnosis to diagnosis of terminal disease	Using the nomogram a probabilistic estimate can be calculated for survival at 15, 30, and 60 days
Prognosis in palliative care scale A (PiPS-A)[276]	Performance status; anorexia; dyspnoea; global health; breast cancer; male genital organ cancer; distant metastases; bone metastases; liver metastases; mental test score; heart rate; dysphagia; and weight loss	Categorical survival prediction: days, <14 days; weeks, 14–56 days; months+, >56 days
Prognosis in palliative care scale B (PiPS-B)[276]	Performance status; anorexia; global health; male genital organ cancer; distant metastases; bone metastases; mental test score; heart rate; fatigue; lymphocyte count; white cell count; neutrophil count; c-reactive protein; albumin; platelets; urea; alanine transaminase; and alkaline phosphatase	Categorical survival prediction: days, <14 days; weeks, 14–56 days; months+, >56 days

Table 3: **Summary of characteristics of palliative prognostic tools**

models (PiPS). Two scales, PiPS-A and PiPS-B, have been created so that a prognostic score can be calculated regardless of whether or not blood test results are available. Both scores have subsequently been validated by external groups.[287,288] The PiPS scales produce a categorical output such that patients are stratified according to whether they are likely to live for days, weeks, or months (or longer).

Only a few studies have directly compared the performance of the different prognostic tools, and no clear pattern emerges. The PiPS tools have been directly evaluated against clinician predictions of survival. Gwilliam and colleagues[276] reported that the PiPS-B tool was significantly more accurate than a doctor or nurse's estimate of survival, but was not statistically significantly more accurate than a combined multidisciplinary team estimate. The PiPS-A and PiPS-B were also reported to be better at predicting short-term prognoses than the PaP, D-PaP, or PPI, but not as good as the D-PaP at predicting longer-term prognoses.[288] The same study reported that the PiPS-A and the PPI were the most feasible tools to use in clinical practice (routine data available for >90% of patients). The PaP has been shown to perform better than, or as well as, the PPI[289,290] or the PPS,[291] but not as well as the Feliu Prognostic Nomogram.[275] Chou and colleagues[292] reported that the PPI performed better than the mGPS in patients with haematological malignancies under palliative care. A large (n=1778) prospective comparative study (ISRCTN13688211) comparing the accuracy of the PiPS-A and PiPS-B tools with the PaP, PPS, Feliu Prognostic Nomogram, PPI, and Glasgow prognostic score, is currently underway in the UK and is due to report in 2019. Importantly, this study also includes several clinician predictions of survival (probabilistic and temporal) to act as comparators.

Although accuracy is an important factor when the relative merits of different prognostic tools are compared, other factors should also be taken into consideration. Steyerberg and colleagues[293] emphasised the importance of studies assessing the effect of prognostic tools on clinical practice and outcomes. The best method for such studies is a cluster randomised controlled trial, but none have been done in the context of palliative care. Impact studies are required to determine whether more accurate prognostication would lead to earlier referral to palliative care services, more advance care plans being prepared, more home deaths, less intensive treatment in the last weeks of life, and greater satisfaction with communication and with care.

In conclusion, the current state of knowledge is insufficient to make a definitive recommendation about the best prognostic tool to use. Nonetheless, there is good evidence that clinicians' estimates alone are inaccurate and are, generally, overly optimistic. These estimates should be complemented by the use of objective prognostic tools wherever possible.

Communication of prognosis

For prognostic tools to provide benefits for patients, the clinician must communicate the estimates produced (including the associated uncertainty) and the implications for treatment clearly and with empathy, so that the information is understood and can be used by the patients. Proper prognostic evaluation and sharing the results with the patient are core clinical skills in integrated oncology–palliative care. Communication of prognostic information is one of the fundamental tasks in the provision of patient-centred care. For a broader presentation of communication tasks see the section of this Commission on patient-centredness.

Clinicians have a duty to fully inform patients about treatment intent and its risks and benefits; this communication is particularly important for SACT because patients often have unrealistic expectations about its potential benefits.[250,251] Although most patients are told that their cancer is incurable, physicians have a tendency to steer the conversation towards treatment, engage in collusion with patients' false optimism, and sometimes fail to check that their patients have understood the purpose of SACT.[294–297] Studies[297,298] have reported that 50% or fewer patients were offered alternatives to SACT in consultations, and that clinicians often described palliative care as doing nothing, rather than discussing its potential benefits. The increasing number of lines of chemotherapy and novel therapies further adds to the uncertainty facing the informing physician. This uncertainty points to the need to adhere to one of the basic principles of prognostication: it is not an event, but a process.[299] Furthermore, the patients' and relatives' wishes for prognostic information will vary over time.[244] The patients' wishes for exact information decreases as death approaches but is, in general, ambivalent.[244] Involving patients in a continuous discussion of their prognosis might influence their future goal setting, enabling them to set a goal other than survival.

There are a range of patient, physician, and institutional barriers to clear communication about prognosis and palliative care in oncology. Oncologists describe a cure culture in which they are trained to treat, and so can feel that stopping SACT is a sign of failure, often resulting in discussions about hospice being delayed until all treatment options have been exhausted.[300] Physicians report little confidence in this communication, particularly related to uncertainty about prognosis, leading to concerns that an inaccurate prediction could reduce patient trust.[301] They also express concerns that breaking bad news could lead to depression and a loss of hope in patients.[302]

Despite these perceived barriers, clear communication about prognosis early in the disease trajectory must be the aim within oncology. By contrast with the concerns of many physicians, it is possible for patients to maintain hope following the disclosure of a poor prognosis.[303] Mack and Smith[304] argue that this is a common misconception, and point to evidence that honest discussions,

even when the news is bad, contribute to better physician–patient relationships that foster hope. A narrative review[305] found that avoidance of prognostic discussions can lead to mistrust, anxiety, reduced quality of life, and family distress.

Given the focus on quality of life in palliative care, satisfaction with communication is, perhaps unsurprisingly, higher for bereaved relatives in hospice settings than hospitals.[306] Therefore, earlier integration of palliative care specialists might increase patient prognostic awareness, and improve patient and caregiver satisfaction. In randomised trials integrating palliative care from the time of diagnosis, including regular appointments with a palliative care specialist, Temel and colleagues[3,50,307] found that early palliative care interventions improved quality of life, prognostic awareness, and communication about end-of-life preferences.

In addition to the involvement of palliative care specialists early in the disease trajectory, oncologists need practical advice on communication strategies to integrate early and honest discussions about prognosis and palliative care into their own practice as part of an SCP. Some guidance on strategies that can be used during conversations about prognosis and other end-of-life issues is given in panel 5.

In a review and synthesis of best practices, Bernacki and Block[305] suggest the use of a conversation guide to ensure key topics, such as goals, fears, and trade-offs (ie, prolonging life through intensive treatment *vs* quality of life) are covered. Several discussions might be needed to allow for a step-wise approach that develops prognostic awareness,[309] and to adapt information provision as the disease progresses and the patient's communication preferences change.[26,310] Raising these issues early in the disease trajectory allows the time needed for such a step-wise approach. From the patient's perspective, adjusting their hopes and expectations for the future—from where they are to the factual situation—is, for most, a process that takes time. The conversation guide suggested by Bernacki and Block[305] might be particularly useful as a starting point for clinicians with little experience of prognostic conversations. For clinicians who will be having regular prognostic discussions, more focused communication training about cultivating prognostic awareness might be appropriate.

Systematic reviews of training to improve clinicians' end-of-life communication and communication with patients with cancer have reported some positive results, such as increasing expressions of empathy, increased use of open ended questions, and improved clinicians' self-efficacy and comfort with these conversations.[311,312] However, more evidence is needed about the effect of training on patient satisfaction, whether positive effects are sustained over time and on other outcomes, such as quality of patient death.[311,312]

Barriers and solutions

Accurate prognostic information is needed by both patients and clinicians to help inform treatment decisions. Clinicians' survival predictions are frequently inaccurate and overly optimistic. Professionals working in oncology often do not have confidence in communicating poor prognoses and related uncertainty, resulting in these conversations being delayed or omitted, and in patients having unrealistic treatment expectations. Some of these barriers could be overcome by the use of objective prognostic tools to complement clinical intuition; however, further research will be required before definitive recommendations can be made. Earlier integration and increased collaboration between oncology and palliative care might improve the quality of communication and reduce the frequency of futile treatments in patients approaching the ends of their lives. Evidence-based communication guidance and training (as part of a wider integration of palliative care and oncology education; see the section of this Commission on the role of education) to provide practical strategies for the communication of prognosis and uncertainty would reduce barriers to prognostic awareness among patients (panel 6)

Panel 5: **Australian clinical practice guidelines for communication of prognosis and end-of-life issues**

- Assess what the patient already knows and the level of detail they want
- Tailor the information to the individual and their family: pace provision of the information depending on the individual, use non-technical language, consider the family's individual needs
- Acknowledge uncertainty and avoid giving exact timeframes; be honest without being blunt
- Explore and acknowledge emotions
- Encourage questions, check understanding, and emphasise continuing care

Panel adapted from Clayton and colleagues.[308]

Panel 6: **Prognostication—recommendations**

- Prognostic communication about life expectancy should occur early in the disease trajectory as a part of early integration of palliative care, which can be achieved by teaching oncologists and palliative care physicians how to convey prognostic information, and establishing national and international indicators of patient involvement in the prognostic process
- Develop new prognostic tools to predict survival, symptom control, and maintenance of functions (physical, mental, and social) during cancer palliative care by allocating research resources and establish international collaboratives to develop the prognostic tools

Patient-centredness—content, method, and clinical implications

The Institute of Medicine defines patient-centredness as, "care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions".[313] This approach is recommended in all areas of medicine, but its content and methods have been considered particularly appropriate in cancer care.[314] Central to this approach is patient-centred communication that aims to foster healing relationships, exchange information, respond to emotions, manage uncertainty, make decisions, and enable self-management.[315] Patient-centred care is dynamic and should involve a step-wise approach addressing the patients' physical, psychological, social, and spiritual needs at all stages of the disease.[313] These needs must be assessed and documented dynamically because they are likely to change over time and will be used in the decision-making process in consultations, multidisciplinary team meetings, or other clinical decision points.

Increasing research attention is being paid to value-based care in cancer, which refers to the quality of care achieved, modified by the cost.[316] Up until the past two decades, patient-reported outcomes were not included in the research evaluation of the quality of cancer care, and unfortunately the clinical focus still tends to be disease centred, rather than patient centred. This focus has contributed, at least in high-income countries, to the overuse of some cancer treatments, including those that are futile, and to the rising cost of cancer care.[317] The use of PROMs in clinical trials and some clinical practices has facilitated the shift to greater patient-centredness in cancer care.

Systematic symptom assessment is an important component of patient-centred care. Studies[75,76] done in the past few years have shown the positive effects of systematic symptom assessment on patients' quality of life, and possibly also survival. However, despite the overwhelming evidence of the benefits of systematic symptom assessment, implementing such assessments in routine cancer care has been slow because of concerns about its feasibility, benefit, cost, and the absence of a strong enough system of implementation with economic or professional incentives, or both, and a patient-centred focus.[72,76,126,318,319]

Adequate communication skills are necessary to provide patient-centred care. Patient-centred communication can be learned,[320] and must be regarded as a professional skill, rather than merely a personal attribute. This competence is needed to assess symptoms, provide information about diagnosis and disease progression, and to discuss options and patients' preferences for treatment and care.[315] Such skills are of importance throughout the entire cancer trajectory, but might be particularly relevant when the treatment intention is non-curative, or the biological effects of tumour-directed treatments might be minimal and the adverse effects on quality of life might be substantial. Evidence exists that oncologists might have significant deficits or shortcomings in their emotional engagement and communicative skills with their patients,[321] and that both empathy and communication skills can be improved with training.[320,322]

Patient-centredness has been central to contemporary palliative care since its emergence in the 1960s. At that time, patients did not receive palliative care until near the end of life, when it was clear that symptoms, needs, concerns, and relationships would be the primary targets for interventions. Palliative care is now recognised as potentially of value from the time of diagnosis, but the focus on patients and families has remained central to palliative care. Quality of life and symptom alleviation are primary targets of treatment in palliative care, and communication and SDM are considered essential methods of practice.

SDM has been defined as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences.[323] SDM involves both the patient and the physician, and helps to ensure that there is informed consent and patient autonomy in decision making. SDM presupposes that the patient has knowledge of the disease, intended effects and toxicity of treatments, expected survival, and symptom burden with and without the proposed treatment. SDM requires a trusting relationship between the patient and the health-care providers, and communication skills on the part of the health-care providers. Such skills are needed to facilitate the appropriate, timely, and sensitive sharing of relevant information, and to support patients in expressing their preferences and views, and in making truly informed choices.[324]

Advance care planning (ACP), a particular variant of SDM, focuses on the patient's priorities for the future, including dying in accordance with their personal values and wishes. ACP is an important aspect of contemporary cancer palliative care,[324] recommended to take place early in the course of treatment when cure is not an option. Engagement of patients and families in ACP can help them to reflect on, and manage, the transitions that lie ahead, and to set treatment goals that are consistent with their values and preferences.[325]

The integration of palliative care and oncology highlights the importance of patient-centredness, including skills in communication, SDM, and ACP. Although responsibilities of oncologists and specialists in palliative and supportive care should be divided to some extent, communication and interaction between them is important to support a common understanding of the disease and the treatment. Feeding back palliative medicine specialists' observations to oncologists might help to ensure that patients are truly informed and do not have unrealistic expectations about the goals and results of the tumour-directed treatment, ensuring they can meaningfully participate in SDM.[326]

Patient-centredness in palliative care and oncology settings

Cicely Saunders[31] established modern palliative care, highlighting the importance of active listening to patients' needs, and making patients' views visible and recognisable in the care processes. She also introduced the concept of total pain,[327,328] which infers a broad understanding of the patient's needs during a life-limiting disease. Saunders was a pioneer in patient-centred care, although this term had not yet entered the medical lexicon at the time.

Some characteristics of contemporary cancer care are of relevance to the promotion of patient-centredness as a means to improve care. Most patients experience cancer as a chronic disease, although the public perception of cancer is probably more closely aligned with the acute disease model.[329] The chronicity of cancer stems from the fact that many patients either undergo life-prolonging treatments for years, or are cancer survivors with manifest or latent distressing symptoms and signs. The chronic disease model has become even more relevant to cancer over the past few decades, with the advancement of modern surgery, chemotherapy, radiotherapy, targeted therapies, and various types of immune therapies. Cancer treatments are often combinations of different treatment modalities administered by different specialists, and each treatment carries its own risks and benefits. Navigation of such complex systems therefore becomes a core task in itself, which the patient cannot be expected to solve alone.

To be actively involved in the care planning, the patient, and eventually their family, must understand and accept the reality of the situation, and the options at hand. Many patients' understanding of their disease is far from their medical reality. Combined with the distress that accompanies the cancer disease trajectory,[330] the physicians meet patients who are often misinformed or under-informed, and have compromised decision capabilities due to distress. These patients are, therefore, at high risk of accepting treatment proposals with uncertainties that they are not aware of. This situation places a great responsibility on the physicians because they might begin treatment of patients who are not truly informed about the risks and benefits of the treatment. The high percentages of patients misinterpreting palliative radiotherapy or chemotherapy as curative support this understanding.[331]

Patient-centred care is a broad approach that must take into account both the person and the disease, with attention to individual values, needs, resources, and preferences (panel 7). Health literacy[332] (ie, the ability to obtain, read, understand, and use health-care information) might vary widely across patients, and must be taken into account in communication and SDM. Various factors, including anxiety related to the life-threatening circumstance, language, culture, and recent immigration, might affect health literacy and the ability of patients to participate in decisions about their care. The fragmented nature of the cancer care system, with multiple levels of care, providers, and locations, also presents major challenges to coordinated care and the development of comprehensive treatment plans.[333]

Panel 7: **Main elements of patient-centred care**

- Respect for patients' values, preferences, and expressed needs
- Coordination and integration of care
- Information, communication, and education
- Physical comfort—relief of bothersome symptoms
- Emotional support—relief of fear and anxiety
- Involvement of family and friends

Shared decision-making (SDM)

SDM is a central component of patient-centred care and is highly relevant in all phases of cancer treatment, but becomes increasingly important as the disease progresses. Decisions often become more complex with disease progression, with trade-offs between life quantity and life quality. SDM is an active process, requiring the exchange of information and opinions for patients to make decisions on the basis of their values and preferences, and their understanding of the best available medical evidence.[334] This means combining the tumour-directed and patient-centred approaches to care, and weighing the benefits and risks of starting, changing, continuing, or stopping tumour-directed treatment. Decisions about selecting one treatment option over another might also be difficult because there is often little or no empirical data that indicate greater value for one regimen over another.[335,336]

Various factors unrelated to the value of care might affect SDM, including those highlighted by researchers in behavioural economics and the psychology of decision making.[337] Decisions about starting, continuing, or discontinuing chemotherapy or other cancer treatment might be difficult to make because of insufficient, uncertain, or even conflicting empirical data, and because they are made under circumstances of emotional strain. In this situation, available statistical and clinical data might not be used,[338] and some clinicians might find it easier to prescribe another round of chemotherapy than to engage in a conversation about futile treatment.[337] The last-case bias might operate in situations in which decision makers are more influenced by recent experiences than by remote events. Reimbursement practices might also directly or indirectly influence institutions and providers toward chemotherapy that is costly, but of uncertain benefit. Patients and providers might tend to be treatment focused in such situations of uncertainty[339] because they hope that treatment will prolong survival, or because physicians are uncomfortable having conversations regarding prognosis.[339] Correction of misbeliefs about quantity of life and introduction of alternative treatment goals, such as preserving quality of life, require

	Physician's premises	Patient's premises
Physician makes the decision	Physician makes the decision without access to patient's preferences	Patient is not competent to give informed consent
Physician limits the patient's preferences	Physician clarifies available treatment options	Patient wants a treatment that is not available
Physician makes decision in collaboration with the patient	Physician recommends a defined treatment	Preferences and wishes for shared decision-making might vary
Patient makes the decision during the consultation with their physician	Physician presents equivalent or similar treatment alternatives	Preferences and wishes for shared decision-making might vary

Table 4: **Examples of different degrees of shared decision-making**

	Action	Consideration
1	Determine situations in which shared decision-making is crucial	Complexity depends on treatment intent and options
2	Acknowledge that decisions are to be made to the patient	Increasingly important with sensitive issues
3	Describe treatment options, including risks, benefits and uncertainty associated with options	Avoid hastened decisions, make sure patients are fully informed
4	Elicit patient preferences and values, and make sure the patient understands the information in her or his perspective	Listen carefully and convey information in a language that matches the patient's cognitive level
5	Agree on a plan for the next steps in the decision-making process	Agree that the plan might be revised depending on the disease development

Table adapted from Politi and colleagues.[334]

Table 5: **Five steps in shared decision-making**

communication skills on the part of the physician, and are most appropriate within the framework of SDM.

Physicians are legally and ethically obligated to provide information in a way that enables patients to be active and informed partners in the decision-making process and to promote their participation in decision making.[340] A process to accomplish such SDM can be described in four steps: awareness of equipoise, discussion of the benefits and harms of options and their probabilities, elicitation of patients' concerns and expectations, and partnership and participation.[341] Only the second step seems to be common in cancer clinics,[342] where most attention is typically paid to the objective biological aspects, consistent with the tumour-directed approach. Little attention is often paid to the patient's (ie, host's) preferences, symptoms, quality of life and care, and the option of no tumour-directed treatment.

Despite being a central element of patient-centred care, SDM is not explicitly included as an integrated part of oncology guidelines.[15,21] A premise of SDM is that the oncologist and the palliative medicine specialist must both be aware of the patient's prognosis and of the risks and benefits of treatment choices in patients with advanced cancer.[343,344] Patients might have unrealistically positive perceptions of their prognosis and effects of tumour-directed treatments, and be willing to continue or to start therapy with minimal or no likelihood of therapeutic effect and a high risk of side-effects.[331] The use of intensive and non-beneficial treatment at the end of life is both extensive and expensive,[24,257] although such treatments often reduce quality of life and time spent at home.[251] Paradoxically, physicians who develop cancer tend to choose less intensive treatment for themselves at end of life than they offer their patients.[345]

A common misunderstanding is that SDM involves leaving decisions to the patient. As shown in table 4, there are different degrees of SDM, which depend, in part, on the choices at stake. The decision-making process is the main component of SDM.

To promote SDM, the doctor must encourage patients and caregivers to participate in consultations and decisions regarding the care, determine situations in which this is crucial, and inform patients about the benefits and disadvantages of available treatment options. This process must include balanced prognostic information about best-case and worst-case scenarios, responding to patients' concerns and their understanding of the information, which helps to reach an agreed-on treatment plan.[346] This approach largely corresponds with the five-step process presented in table 5. Patients' and caregivers' assertive behaviours and physicians' facilitative behaviours interact to promote patient participation in the decision-making process over time.[347] This complexity explains why a single, unidimensional intervention is less likely to work.[348]

The literature on outcomes of SDM in palliative care is scarce and findings are inconclusive.[349] However, in a range of studies in different groups, SDM has been associated with better quality of life and treatment and consultation satisfaction, better affective-cognitive outcomes, and decisions that are more in line with the patient's preconsultation treatment preference. A 2017 study[350] showed that 50 (49%) of 102 patients with cancer preferred shared responsibility of treatment decisions, whereas 30 (29%) patients preferred to leave the decision to the physician. Older and more distressed patients were more likely to leave the decision to the physician. This corresponds to another study[351] reporting that about 50% of patients with advanced cancer preferred to be involved in SDM, whereas the remaining 50% were almost equally divided between active (ie, making the decisions by themselves) and passive (ie, the physician making the decision for them) approaches. Such attitudes might change over time, in either direction, pointing to a need for individualisation and flexibility in communication and care planning. More research has been done on the use of decision aids, finding increased knowledge, greater patient engagement, and decisions more consistent with patients' preferences as a result of their use.[352]

There is little evidence about patient preferences concerning communication and information as an aid to SDM in palliative oncology.[353] Most patients (90–95%) are more willing to obtain information about diagnosis, prognosis and treatment options than about palliative care (63%).[354] However, about half wish to participate in

treatment decision making as time passes, and patients with more pain are more likely to change their preference towards being more involved.[355] Most patients with advanced cancer say they want honest, sensitive communication about end-of life issues.[356] This kind of communication helps patients and their families to prepare, make informed decisions, and avoid potentially burdensome medical treatments near death.[357]

The role of family and caregivers is important in the SDM process throughout the disease trajectory. Two-thirds of patients with advanced cancer want family members to participate in the communication and decision making;[354] however, caregiver preferences might not be concordant with those of the patient,[358,359] especially regarding information when death nears.[343] Some patients with cancer might want to spare family members from the emotional strain of receiving bad news, and distress in caregivers of patients with advanced cancer is reported to be greater than in the patients themselves.[360]

Successful implementation of SDM in clinical practice relies on training physicians to engage with the patients and provide the right information at the right time. Several decision aids exist to facilitate this process,[21,334] and the step-wise approach presented in table 5 is a systematic approach. Specifically defining SDM as a part of the standardised care pathways might promote its implementation in clinical practice at the organisational level and the individual patient care level.

Advance care planning (ACP)

ACP can be considered a variant of SDM, focusing on the patients' voluntary participation in discussing their future care with their care providers. ACP should be an integral part of the care and communication process, and of the regular care plan review. ACP differs from regular care planning by focusing on anticipated deterioration in the individual's condition approaching death. ACP was developed from advance directives, which have been used in the USA and other countries since the mid-1970s.[361] From the mid-1990s, the focus of advance directives shifted from standardised legal forms to an ongoing and flexible process, and from refusal of treatments to promotion of statements of preferences and wishes, paving the way for ACP.[361,362] ACP has received growing attention since that time, and is now an important issue in palliative care internationally.[324,363] In Europe, efforts to promote ACP have been focused on patients with life-limiting illnesses, rather than on the general public.[364,365] Although advance directives are specifically directed at refusing treatment when individuals are no longer able to express their wishes, ACP also concerns future care in a broader sense.[363,365]

A consensus definition of ACP, published in 2017, describes it as "a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of ACP is to help to ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness."[366] The word process underlines that the planning is not a one-time event, but evolves over time through a series of conversations; therefore, ACP documents should be updated regularly.[363,365,367] Although the definition does not specify who should take part in the process, ACP discussions commonly involve the patient, family, informal caregivers, and health-care professionals. This discussion can be had by the primary care or oncology team, or by the palliative care team, depending on the available skills and resources.

The ACP process starts by exploring the patient's health-related experiences, concerns, personal values, and understanding of ACP and readiness to engage in it. Not all patients want such a plan or can formulate their wishes for future care, which is, in itself, valuable information for planning of care. The current disease situation should be discussed next, to obtain a common understanding of treatment and care options and their advantages and disadvantages. ACP might also include discussion and completion of an advance directive or living will, depending on the national legislation. The advance directive will typically address specific interventions, such as cardiopulmonary resuscitation or tube feeding, in a future scenario of incapacity. Finally, encouraging the individual to share thoughts and preferences with family and friends is an important part of the process.[363,365,367]

Different forms and templates for ACP documents have been proposed, and many are freely available on the internet.[368] Debate about whether ACP should be based on open or scripted conversations is ongoing.[324] The use of a template might ensure that the most relevant areas are presented to the patient, although strict adherence to a guide might restrict the free exchange of thoughts, and reduce ACP activity to a tick-box exercise.[365] A semi-structured interview guide might avoid these dangers.[369] ACP ensures that the care is more likely to be in accordance with the patient's preferences than if it is not done.[370] It has also been shown to decrease life-sustaining treatment at the end of life, increase the use of hospice and palliative care, and prevent unwanted hospital admissions.[357] Comprehensive ACP programmes seem to be more effective in making end-of-life care coherent with patients' preferences than completing a written advance directive.[371]

Although unresolved questions as to the optimal ACP system and how to assess the impact and effectiveness of the system remain, ACP is coherent with patient-centred care and therefore relevant for the early integration of palliative care and oncology. Presently, many countries do not have any legislation regarding ACP, which we think is necessary for successful integration of palliative care and oncology.

Systematic assessment of the patient's perspective

Symptoms, preferences, and patient-reported outcomes have had many different labels over the past three to four decades. The FDA proposed the term PROMs for all measures that can best be assessed by patient self-report.[66] PROMs is an umbrella term covering the patient's perspective on wellbeing, symptoms, subjective treatment effects, and side-effects.[67] The CONSORT-PRO Extension Statement, which aims to improve the reporting of PROMs on symptoms, functioning, and quality of life,[69] further consolidates PROMs as independent outcomes in cancer.[68,69]

The patient perspective and experience cannot be replaced by clinical observations and examinations by the oncologist or palliative medicine specialist. In ordinary consultations, many symptoms are not identified or addressed;[372] however, PROMs can be used to highlight the patient's experience and bring the patients' voice into the clinical consultations. The benefits of routine assessment of PROMs in clinical practice are well documented, including improved patient–physician communication,[373–375] increased physicians' awareness of patients' physical and psychosocial functioning,[376–378] improved patient wellbeing,[75,374] and a more efficient and focused use of time.[377] Regular use of PROMs makes the physician aware of symptoms they did not know affected their patients.[378]

Knowledge of symptoms is essential information for the primary cancer diagnosis and for follow-up care during curative and life-prolonging treatments; however, systematic symptom assessment is not part of routine oncological care[376,379–381]—although it is frequently used in clinical trials.[382] For patients with advanced cancer, for whom symptom management is a central goal of care, systematic use of PROMs is even more important, and is a prerequisite for optimal symptom management. Relieving burdensome symptoms is therefore a core task within patient-centredness, and a special obligation on the part of the physicians.

Insufficient and unsystematic assessment of symptoms is a major factor explaining inadequate symptom relief in patients with cancer. Inadequate pain control has been documented in up to half of patients,[383] despite efforts to improve pain treatment.[383,384] Clinical studies of patients with cancer have found systematic use of PROMs to improve a range of symptoms, including pain.[377]

For patients with limited life expectancy, the balance between treatment effect and tolerance of therapy is crucial in treatment decision making. Reporting of toxicities and adverse effects in clinical trials, by such systems as the Common Terminology Criteria for Adverse Events (CTCAE, version 4.0) developed by the National Cancer Institute, is mandatory. Until about 7 or 8 years ago, the CTCAE were rated by physicians, although many criteria are symptoms that are best reported by the patients. This recognition has led to the development of a PROMs version of the CTCAE—the PRO-CTCAE.[385]

The most feasible and reliable form of PROMs is via standardised and methodologically sound self-report questionnaires, which are traditionally paper-based. New advances in health information technology have led to the development of electronic tools for the collection of PROMs. Electronic data collection permits dynamic assessment—ie, automatically tailored questions for individual patients based on the patient's previous scores on given symptoms. This dynamic assessment results in fewer repetitive and irrelevant questions, reducing patient burden. Several electronic questionnaires, so-called e-PROMs, now exist, with a user-friendly interface and immediate aggregation, storage, and transfer of patient scores for direct use in the clinical encounter and possible integration with other clinical data in the electronic patient record.[386] In the oncological setting, electronic assessment and rapid presentation of results to the clinician facilitate communication, are well-accepted by patients and clinicians, and might result in more efficient and focused use of time.[71] A 2012 qualitative study[73] showed that perceived usefulness might be more important than functional aspects regarding applicability; however, immediate display of easily interpretable results to the physician is a crucial factor for successful implementation of electronic identification of PROMs in the clinics.[74] Nevertheless, the most important obligation on the part of health-care providers is to actively use PROMs tools, discuss the scores with the patient, explain potential interventions, and make the patient an active partner in the decision-making process.

Systematic symptom assessment by either paper-based or e-PROMs ensures registration of burdensome symptoms, such as anxiety and depression. This process is important because patients often do not report such symptoms unless asked, particularly if they perceive that they will not be regarded as relevant to their cancer care. The symptoms reported by the patients with PROMs must be addressed in the clinical encounter and used in the decision-making processes. Intensity is the most common dimension that is investigated in the assessment tools, but must be supplemented with other symptom characteristics. The duration of the symptom, its meaning, and the distress associated with it might best be elucidated in a follow-up clinical interview. Initially, this assessment might be done in an oncology clinic, but a more in-depth assessment might be done by the specialised palliative care or psychosocial oncology team to be able to provide more specialised care.

Caregiver involvement

Patient-centred care and SDM aim to involve the family members of patients. In clinical care, patients should be routinely asked to identify their significant others, and to provide information about the nature of their relationship, strengths and limitations in their ability to take on complex cancer caregiving, and how much information

about the medical situation they can and should receive. Caregiver problems, such as serious illness or emotional or economic problems, also need to be assessed.

Caregivers are often actively involved in decisions about the care and treatment of a patient with cancer, particularly decisions focusing on the end of life. Patients choosing to participate in SDM are reported to prefer to share this experience with their family members.[387] Caregivers, including family or friends, often provide care for patients with cancer, although many might not be well prepared to do so. The burden of such caregiving might be substantial, and reduced quality of life, distressing symptoms (eg, insomnia, fatigue, anxiety, and depression), and financial stress have been shown to be common among caregivers.[388,389] The strain on caregivers might have increased in the past 20 years, because cancer care has shifted towards outpatient and home-based care. Moreover, with cancer being more prevalent in the elderly, many caregivers are of advanced age and might suffer from substantial health problems of their own. Involvement, training, and support of caregivers are, therefore, key components of modern cancer care.

Caregiver resources, the quality of the support for the patient, and the quality of the caregiver support might have a decisive influence when the disease progresses and decisions need to be made about the place of care and the location of death.[390] Family members, as informal caregivers, are often the patient's main source of emotional and practical support, although the burden and challenges of disease might create or intensify family conflict. Such conflict, which can obstruct or complicate treatment planning, might benefit from intervention; however, these disagreements can be challenging and time-consuming to resolve. Palliative care physicians and teams can help to support caregivers in addressing these conflicts, though engagement of specialised psychosocial oncology might also be of value. The updated ASCO Clinical Practice Guideline[15] on integration of palliative care and oncology emphasises that services by multidisciplinary palliative care teams complement existing programmes, and "Providers may refer family and friend caregivers of patients with early or advanced cancer to palliative care services."

Studies of the effects of early provision of palliative care on caregiver satisfaction with care, quality of life, and emotional distress have produced conflicting results. A Norwegian study[391] showed an overall positive effect on quality of life, in line with studies of caregivers of patients with a poor prognosis treated by specialty trained palliative care clinicians.[392–394] The ENABLE III study by Dionne-Odom and colleagues[395] was probably the first randomised trial to examine a specific palliative care intervention for family caregivers of patients with advanced cancer. The intervention group received three structured telephone coaching sessions each week and monthly follow-up and bereavement calls, whereas the control group received usual care. The results showed significantly lower depression scores at 3 months in the intervention group.

Two consecutive meta-analyses[388,389] have examined the effect of different interventions on various caregiver outcomes in a total of 79 randomised trials with family caregivers of patients with cancer. Results from the first analysis[389] indicated these interventions had small-to-medium effects on caregiver burden, ability to cope, self-efficacy, and aspects of quality of life. In the period covered by the second analysis[388] (2010–16), the number of trials had increased substantially, corresponding to a huge variety of formats and types of interventions. This variability makes comparisons and conclusions about efficacy difficult, but indicates caregiver interventions can vary and probably should be flexible.[388] In most randomised trials of early introduction of palliative care, caregiver satisfaction is, at best, defined as a secondary outcome, and therefore can be interpreted as a complementary effect of improved patient care, and not the result of specific interventions directed at the caregivers.

Qualitative data from trials of early palliative care have identified certain aspects of palliative care that might influence the caregiver satisfaction; eg, building rapport, establishing a relationship with patients and family, focusing coping, and providing realistic information about prognosis.[326,396] The content of the early and subsequent palliative care visits, identification of key issues, and timing of when to address these were regarded as reasons for favourable outcomes in one study.[326] Statements expressed in another study[396] gave important clues as to how incurable cancer affects the family and ways that helped them cope. Statements like, "It is the family that's going through it", and "Talking with the palliative care physician was immensely advantageous", clearly illustrate these points.

Communication—a key to patient-centredness

Oncologists and palliative care specialists face difficult communication situations throughout the trajectory of cancer, including breaking news about disease progression and non-response to tumour-directed treatments. A strong focus on better communication as part of early palliative care promotes patient-centred care, and results in improved prognostic awareness and patient satisfaction.[5,307]

Patient-centred communication is a key asset for the implementation of SDM in oncology practice. As mentioned earlier, the main characteristics of patient-centred communication are attention to the patient's affective states, values, needs, and preferences.[340] Patient-centred communication aims to create a dialogue between the physician and the patient; therefore, the clinician must be able to monitor and consciously adapt the communication to meet the patient's needs. When this does not occur, the communication takes the form of a monologue that is provider-centred and not patient-centred.

Panel 8: Communication in the cancer care setting

Communication will help patients to:

- Receive bad news
- Handle the emotional impact of a life-threatening illness
- Understand and remember complex information
- Communicate with multiple health professionals
- Understand statistics related to prognosis
- Deal with uncertainty while maintaining hope
- Build trust that will sustain long-term clinical relationships
- Make decisions about treatment, possibly including participation in clinical trials
- Adopt health-promoting behaviour

Panel adapted from Epstein and Street.[315]

Panel 9: Advanced cancer

Key communicative tasks to be solved

- Elicit the patient's report of symptoms
- Communicate prognosis while maintaining hope
- Make decisions about tumour-directed and intensive medical treatments—particularly about starting and stopping criteria
- Make decisions about future care, including hospice care
- Respond to the emotions of the patient, family, and caregivers
- Help the patient navigate the transition to end-of-life care

The key tasks to be solved by patient-centred communication span the whole cancer trajectory, but common features to all phases are exchanging information, responding to emotions, fostering healing relationships, managing uncertainty, making decisions, and enabling patient self-management (panel 8).[346] Patient-centred communication transcends medical issues and also includes practical issues, such as clarification of responsibilities and who to contact.[305] Key communicative tasks to be solved in advanced cancer are presented in panel 9.

Communication includes both the sending and receiving of information, with both verbal and non-verbal elements. Both parties must repeatedly change roles from sender to receiver; being the receiver (ie, performing active listening) is challenging for many physicians. One of the most cited studies[397] of physicians' communication showed that general practitioners interrupted the patient, on average, 18 seconds after the patient had started talking. Physicians must be willing to see patients as whole people and provide them with information that is understandable and useful from their perspective. Physicians must also be prepared to discuss the end of life, although the words die and death are generally avoided by oncologists, who might be uncomfortable engaging in meaningful discussions about the end of life.[398] Honesty is commonly believed to undermine hope, although there is evidence that honest but empathic communication might actually help to preserve morale and psychological wellbeing.[230] Finally, both parties need to share knowledge and understanding, and must have suitable perceptual and linguistic skills to produce effective communication behaviours that are appropriate to the situation.

For patients, good communication with their physicians can help to make them feel understood, participate actively in the interaction, improve their understanding of the disease and treatment options, cope better, and trust in their physicians and the health-care system. Patient-centred communication can also result in a treatment plan that is concordant with the patient's preferences and values. The establishment of a common understanding of the current situation between the patient and physician is essential as the starting point for patient involvement. Prerequisites to good communication are the use of a mode of delivery and language that match the patient's cognitive and intellectual abilities, and the consideration of the patient's emotional state at the time of the consultation. Hence, provision of sufficient information requires knowledge about how to convey the information in an understandable manner at the right time.

With more complex clinical conditions and therapeutic opportunities, patient-centred communication is especially salient.[399,400] Nevertheless, although listed as a key dimension of patient-centred communication, inadequate communication about prognosis and treatment choices is common.[343,344,401] Crucial information about prognosis and treatment options is often not discussed during life-prolonging treatment, and might lead to unrealistic patient expectations regarding cure.[3,307,346] Much too often, these discussions take place late in the disease trajectory, often in the last month, which is too late for patient and family to benefit from referral to palliative care.[402]

The tendency of physicians to avoid honest communication is not supported by empirical research. Parker and colleagues[343] found that up to 90% of patients with advanced cancer want information about the disease, treatment options, symptom management, and life expectancy. Evidence that early discussions about care goals in advanced disease improve end-of-life outcomes is accumulating.[305] Patients who have discussed the future with their doctor before the disease is too far advanced report greater wellbeing and have fewer unwanted intensive interventions in the last weeks of life, with no detrimental effect on survival.[3,357] Earlier integration of oncology and palliative care with patient-centred communication enhances patient and family involvement, guides decision making, and promotes realistic expectations for the future. Therefore, patient-centred communication is important for the improvement of general oncology care.[396]

Communication skills can be taught to medical undergraduates and postgraduates, but discussion of prognosis and at relevant timepoints must also be part of oncology and palliative care training. Such discussions presuppose detailed knowledge about prognosis, including the uncertainty inherent in a prognostic evaluation. Empathic communication about prognosis and uncertainty are communicative skills that should be mandatory in the curriculum for oncologists and other clinical specialties treating patients with cancer (see the sections of this Commission on prognostication and the role of education).

As outlined in the scheme for SDM, treatment options should be explained simply and clearly. Most topics are emotionally loaded for the patients and their family members. Learning how to elicit and respond to emotions during the consultation while still carrying it forward is a skill that physicians must acquire. Very few physicians learn these skills by themselves: some improve through engagement in an open professional culture focusing on treatment of the patients, and most probably need specific training.

Training in SDM as a method in clinical practice and on how to maintain, develop, and share fundamental communication skills, is needed at regular intervals for oncologists, palliative care specialists, and other health-care providers to foster patient-centred communication.[326,403] Empathic listening, flexible and attuned responsiveness to the shifting needs of the individual patient, and to patients' and caregivers' emotions are important skills that can be improved;[305,309,396,404,405] however, the best methods for improving communication skills are not yet established.[406] Interventions such as communication skills training with role play and feedback, e-learning, group discussions, modelling, case evaluations, and coaching are some of the most commonly used strategies. Strategies that involve activity and practice are most efficient.[406] Although less common, interventions that aim to influence the patient's behaviour, including encouraging them to use prompt lists, can be combined with patient and oncologist coaching.[407,408] Although evidence about their usefulness in palliative care patients is scarce, these interventions could help to engage patients and physicians in more active and deep interaction.[334,409,410]

Psychosocial care

The prevention and alleviation of psychological and social distress in patients with cancer and their families, and support for their personhood has been a central goal of palliative care since its inception.[411] Palliative care emerged, in part, in response to the neglect of the human dimensions of suffering in modern medicine.[412,413] Nevertheless, much less attention has been paid to training and the systematic delivery of psychological and spiritual care in palliative care, as compared with physical interventions, for which there are well developed protocols and guidelines. This contrasts with findings[414] that depression is the main factor associated with poor quality of life in patients with advanced cancer.

Symptoms of depression,[330] demoralisation,[415] and spiritual distress[416] are common in patients with advanced cancer, and longitudinal research[417] has shown that, without intervention, these symptoms tend to worsen with greater proximity to death. Evidence of the effectiveness of psychological interventions to alleviate depression and other manifestations of distress in patients with advanced disease is growing. These interventions include supportive-expressive group therapy,[418] meaning-centred psychotherapy,[419] problem-solving therapy and behavioural activation,[420] and dignity therapy.[421] However, at present, psychosocial interventions and skills are not well integrated into either oncology or palliative care.

An approach to psychological care of the patient with advanced disease that is integrated with both cancer care and palliative care is the Managing Cancer and Living Meaningfully (CALM) approach, developed in 2014.[422] This intervention is intended to provide patients and their caregivers with reflective space to communicate their experience, and to address the major decisions, burdens, and adaptive challenges of advanced and progressive disease. Palliative care, oncology, and psychosocial care providers can be trained to deliver this intervention, and such training has the potential to enhance their ability to engage empathically in sensitive conversations and to create reflective space. An international training programme for health-care providers is now underway[423] for this intervention, which has been shown to alleviate and prevent depressive symptoms, reduce death-related distress, and enhance the capacity of patients to communicate with their family and health-care providers.[424] This programme provides training of members of the multidisciplinary palliative team. The palliative care multidisciplinary team is set up to address the complexity of problems facing the patients and their families. Patients' problems are often complex and cannot be solved by a single profession alone. Some problems are best addressed by specific members of the team—eg, financial problems often need the competence of a social worker. The effects of a multidisciplinary approach have been shown[425] but perhaps not yet fully used. Although a broader patient-centred approach on the part of the physician seems pertinent, other members of the team are often in better positions to provide the care. The CALM approach is therefore promising in terms of its focus on skills needed to provide patient-centred care. The psychological domains are presented in panel 10.

Barriers and solutions

At present, the delivery of cancer care is more provider centred than patient centred,[426] and this situation applies to the system as a whole, including institutions, payment systems, infrastructure, and professional cultures. In

***Panel 10*: Psychological domains of the Managing Cancer and Living Meaningfully (CALM) approach**

Content

- Treatment decisions and communication with health-care providers
- Renegotiation of personal relationships and self-concept
- Reframing of priorities and the sense of meaning in life
- Fears, hopes, and plans related to impending mortality

sum, these factors are substantial barriers to making care more patient centred.

In the public domain, the focus on promising new cancer therapies is prominent. This focus can be traced in present research priorities (see the section of this Commission on societal challenges), and mirrors the priorities and marketing activities of drug companies. The ultimate goal of contemporary science is said to be immortality,[427] and, if correct, this goal is a strong driver for further strengthening the focus on the tumour. These factors also create expectations both within and outside the medical community, and affects priorities at all levels within health care and politics. Public opinion, and thereby the expectations of patients, contrasts with the reality facing a substantial proportion of patients and their families—ie, that their cancer is incurable. In our view, these factors, with their unilateral focus on the tumour, are barriers to a focus that includes both the tumour and the patient.

Oncology as a medical specialty has its roots in internal medicine, while palliative care has its roots outside mainstream medicine. This difference in origin has created cultures with different foci: the tumour and the host. A culture is characterised by sharing the same values, including taboos, and acts as an invisible but commonly shared guidance for social interactions for those sharing it.[428] Bridging of the two cultures in oncology and palliative care is a challenge that is traceable at all levels in health care, including daily activities at wards, departments, and hospitals.

A prominent characteristic of the medical culture has been the perception of the paternalistic doctor deciding on life and death. This was traditionally communicated at medical schools, and still fulfils the expectations of the students to some extent. Most students start at medical school with an inner picture of the physician as the person in power over life and death. For an educator, the most challenging parts of teaching communication skills to medical students are therefore motivating them for the training, and teaching them to systematically explore the perspective of the other—ie, the patient.

The tabooing of death is another observable trait of the medical culture. The word death is seldom used,[398] and many medical schools do not teach palliative care or end-of-life care at all. The lack of exposure to these topics during the formative years as students has future consequences, when these doctors are faced with clinical tasks such as discussing tumour-directed treatments with a patient who has limited life expectancy or providing care that includes death as the endpoint. Physicians commonly use euphemisms when topics are perceived as challenging, often without checking if the information is understood by the patient. This style of communication protects physicians from engaging in challenging communicative tasks because they do not have the skills or the correct answer, despite the fact that open negotiations with the patient would have been preferable.

Even if most patients with advanced cancer express a preference for realistic information and discussions about treatment options and prognosis,[357,429] barriers to high-quality conversations exist on the patient's side as well. Patients might be reluctant to ask questions, express their feelings, or admit they are insecure or do not quite understand the options and the implications. The patient's use of two tongues—ie, one towards the oncologist the other towards other health-care providers—is documented in a qualitative study of patients approaching the end of tumour-directed treatments.[430] This complex communication points to a very important and common trait among patients with advanced cancer: they are conflicted, both wishing to live as long as possible and wanting to live as good a life as possible. This conflict is also commonly observed in relation to wanting information about poor prognosis.

There are examples of how the medical culture has changed in response to new dogma. The best described example is that discussed earlier: the change from hiding to disclosing the cancer diagnosis. In an editorial[431] commenting on Novack's study,[432] which confirmed disclosure to be the preferred practice, informed consent as a prerequisite or inclusion of patients into trials was pointed to as the most possible explanation for the change of attitude.

When asked, doctors are generally positive about the use of PROMs; this positivity is still much more common in palliative care units than general oncology units, primarily because of the enhanced focus on symptom management in palliative care. Frequently cited barriers to the use of PROMs are time constraints, cumbersome use, difficulties related to interpretation, and logistical problems.[380,433] Other factors, including resistance to change of an established system; absence of strong enough implementation; absence of economical or professional incentives, or both; and absence of patient-centred focus, also play a role. These factors are basically the same for all organisational changes, and are a challenge when all types of new practices are implemented. Paradoxically, the introduction of new drugs or technologies does not seem to meet the same resistance to change. It is, therefore, reasonable to assume that the economic strength of the producers of drugs and new technologies plays a role.

To enhance a patient-centred approach, the following factors apply at the organisational, professional, and

personal levels: implementation of a patient-centred approach and communication plan into the SCPs; willingness to change behaviour and incorporate this into clinical practice; and a mutual understanding and internalisation of the content and values of a patient-centred approach among all health-care providers involved in the care.

The problems of information sharing within and between health-care organisations have been recognised as a barrier to the implementation of ACP. Other barriers include the competing demands of other work for health-care professionals, and the emotional nature of these types of conversations. Specially trained staff using a structured approach has been shown to facilitate implementation.[434] Prompts in the electronic health record can increase the rates of documentation.[435] At the patient level, factors influencing the uptake of ACP are complex, including previous illness experiences, preferences, and attitudes. Generally, patients with cancer are more open to ACP than patients with non-malignant diagnoses;[436] however, one systematic review[371] suggested patients with cancer value the SDM and communication elements of ACP more than the avoidance of excessive medical treatment at the end of life.

Other strategies to enhance patient-centredness are elaborated on in other sections and include economic incentives, organisation, and education. Recommendations are presented in panel 11.

Panel 11: **Patient-centred care—recommendations**

- Integrate patient-centred care (focusing on the host) as part of all cancer guidelines and all treatment or care plans early in the disease trajectory until end-of-life care by making societal and political demands at national and international levels, initiated by WHO and professional organisations and patient advocacy groups
- Implement routine use of patient-reported outcomes measures (PROMs) in all settings of patient care by developing PROMs for use in electronic patient record systems and assure that the information is used in the decision-making processes. Implement incentive-driven indicators for the use of PROMs
- Integrate shared decision-making and advance care planning as a mandatory part of all standardised care pathways by refining the methods for shared decision-making and advance care planning internationally, and adapting to national needs and norms; implement incentive-driven indicators for the use of shared decision-making and advance care planning
- Involve and assess the family as a part of early integration of cancer palliative care by developing methods (tools) for involvement and assessment internationally, and adapting nationally and implement indicators to monitor implementation
- Develop the content and basic method of standardised care pathway for use as a tool for early integration of palliative care into oncology care in hospitals and community care by encouraging international research on method development, complementary intervention strategies and plans, training of health-care personnel, and resource set with continuous funding
- Mandatory training of oncology and palliative care specialists in patient-centred care, including patient-centred communication by refining (and further developing) methods for training to be supplemented by international and national accreditations

Models of palliative care integration

The overall aim of integration of health-care services is to coordinate care among providers and across settings, so that patients and their families have access to the care they need when they need it, resulting in improved health outcomes.[42] Thus, a key question is: how should integration or collaboration occur between the two disciplines, oncology and palliative care? Internationally, several different organisational models have been developed, some of which have been tested in clinical studies. Although the content, structure (internally and externally), and professional competence within these models varies considerably, important common themes exist across the models. The aim of this section is to present and discuss models of care, and propose future organisational models.

Over the past decade, several studies and models of care have addressed how the focus of palliative care can be shifted from exclusively end-of-life to early integration within the cancer care trajectory. As highlighted in previous studies,[3,5,47–51] early integration of palliative care improves quality of life, satisfaction with care, symptom control, mood, and understanding of the illness. As a result, several influential international organisations now endorse early palliative care as the standard practice of care for patients with advanced, incurable illness.[15,86,437] The question is no longer whether and why integration of palliative care is worthwhile, but how this can best be accomplished to optimise the goal of better patient-centred care.

Although integration is important for all aspects of health care, it is of particular importance for patients with advanced cancer, who have complex problems that are best managed by a multidisciplinary team.[438] Within the hospital setting, multidisciplinary teams can span various providers, including physicians (such as surgeons, pathologists, radiologists, medical and radiation oncologists, and palliative care physicians) and other health-care providers (including pharmacists, social workers, occupational and physical therapists, spiritual care providers, and music and art therapists). In addition, over the past few decades, cancer care has become increasingly delivered in outpatient, rather than inpatient, settings.[35] For this reason, primary care, including general practitioners and community nurses, are increasingly recognised to play an important role in cancer control, and communication between multidisciplinary team providers across all settings and disciplines is recognised as necessary to improve patient care.[439] The multidisciplinary team approach should, ideally, link oncology and palliative care services in hospitals, and involve and communicate with primary health-care providers as needed. Consideration of how to optimally plan and collaborate between oncology and palliative care services should form an essential component of patient-centred care.

Models of integration—the broad picture

Existing models of integration of palliative care into oncology care can be broadly classified as either

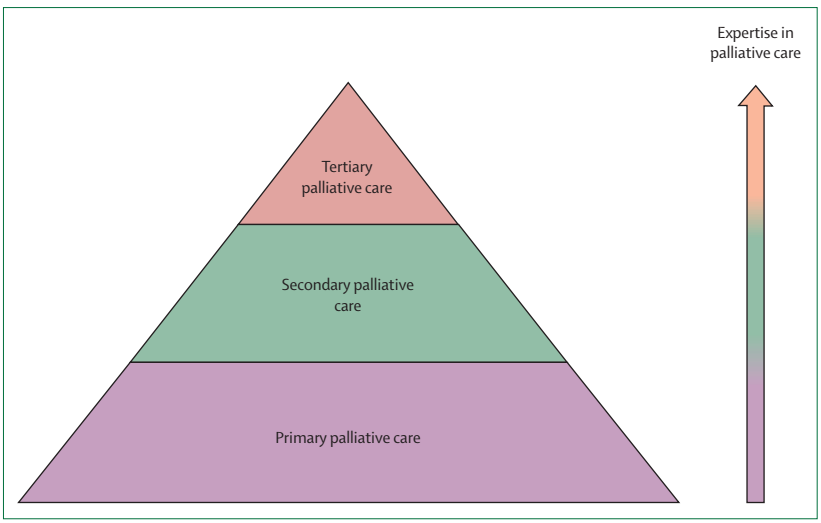


Figure 3: **Conceptual model of palliative care delivery based on provider expertise**

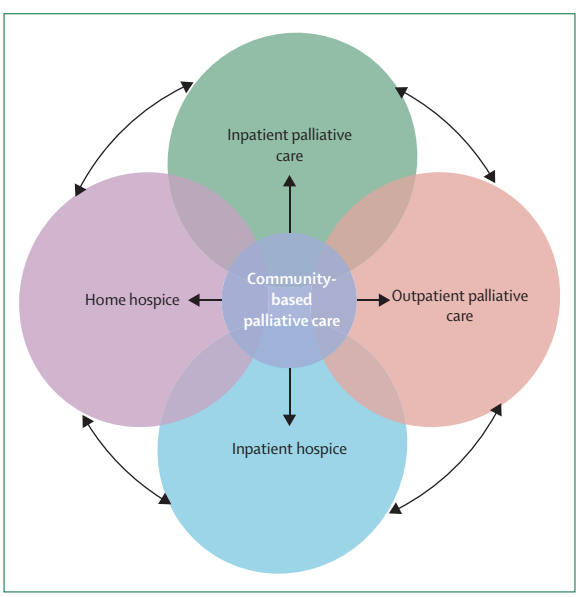


Figure 4: **Conceptual model of community-based palliative care provision**
Adapted from Kamal and colleagues[440]

conceptual or empirical. Conceptual models outline broad theoretical principles, whereas empirical models depict how these principles can be put into action in specific settings.

The conceptual models can be classified broadly into time-based, provider-based, and setting-based models.[148,440] The most well-known conceptual model of palliative care integration is time based. This model contrasts the traditional provision of palliative care only at the end of life with a contemporary model in which palliative care is introduced at diagnosis, and gradually increases until the time of death and bereavement (figure 1). Non-integrated care, in which care is handed over to palliative care teams when the patient's disease no longer responds to tumour-directed treatment, is counterpoised with integrated care, in which palliative care teams provide advice throughout the course of the illness. Other conceptual models are provider based, and classify palliative care, conceptually, as either primary or secondary[441] or primary, secondary, or tertiary[442] on the basis of degree of complexity, and propose the involvement of different care providers at each level (figure 3). Although tertiary palliative care is consistently depicted as being provided by specialised palliative care physicians, variations in the classification of primary and secondary palliative care exist. Primary palliative care is provided by family physicians in some models[443] and oncologists in others.[441] Some models specify that secondary palliative care is provided by oncologists,[444] whereas others classify secondary palliative care as care provided by palliative care specialists in non-tertiary settings.[443] These models emphasise differential competence of providers in palliative care, with increasing levels of competence required to deal with more complex issues.

The third conceptual model of palliative care integration is setting based, in which delivery of care is based on the setting in which care is provided. In these models, the ideal setting for care is proposed to be in the community, with palliative care being provided primarily in the patient's home, rather than in the hospital (figure 4).[440] This community-based care might be provided either by the patient's family physician, with support from a palliative care team,[440] or by a specialist, community-based palliative care team.[445] The emphasis is placed on the facilitation of smooth transitions in care between inpatient, outpatient, home, and community hospice settings.

These conceptual models identify important factors related to organisation, professional competence, and timing as a part of the care pathway, which should be considered when integrated oncology and palliative care across all settings are described and defined. However, no existing models specifically describe the detailed mechanics of how patients move through primary and specialised levels of care or care settings, or how communication occurs among providers. Furthermore, none of these models outline how care is provided within the organisational structures of the oncology health-care system. Full integration requires defined processes, such as clinical care pathways, referral guidelines, or pooled resources, to provide truly integrated care.[42]

The remainder of this section will focus, in greater detail, on a provider-based conceptual model of primary, secondary, and tertiary palliative care provision delivered by generalists, oncology teams, and specialised palliative care teams (figure 5).

This model crosses settings and is not time specific, but emphasises the need for oncology and palliative care to be fully integrated across all settings and levels. Through the use of standardised care pathways and referral guidelines, patients are more likely to be able to

access the right care, at the right place, at the right time. This model is grounded in the concept that most palliative care can, when the treatment goals are cure or life prolongation, be provided by oncologists with basic competence in palliative care. Palliative care specialists should provide consultation for complex problems.[7] We review some examples of empirical models of palliative care within each level of care of this larger model.

Primary, secondary, and tertiary palliative care integration

Primary palliative care

Primary palliative care has been defined as the core skills and competencies that all clinicians should feel comfortable providing to patients with advanced cancer and their families. These skills include basic assessment and management of physical, psychological, social, spiritual, and practical problems; communication related to prognosis and advance care planning; appropriate referral to available community-based supports; and bereavement care for the family.[7] Although primary palliative care can occur at any clinical setting, it is best provided in the community, both in outpatient settings for patients well enough to attend appointments, and in the home setting. Home-based care is particularly important in this context, because it prevents unnecessary visits to the emergency department and hospital admissions, and enables death at home.[446]

Primary palliative care is best provided by multidisciplinary teams that might include general practitioners, home care nurses, personal support workers, and case managers.[447] Although primary palliative care is delivered by palliative care or hospice specialists in some countries, family physicians and general practitioners are well placed to provide primary palliative care. Their therapeutic relationship with their patients and families might span many years, giving them a unique perspective into their patients' values and priorities, potentially including preferences for end-of-life care and advance care planning.[448] A large proportion of patients with cancer have uncontrolled symptoms from the time of diagnosis;[449] thus, family physicians should be sufficiently competent to embark on an initial symptom management plan. As cancer progresses, patients often express a preference to receive care and to die at home, if possible,[450] which might be facilitated by primary palliative care providers.[451] In addition, these physicians support families during bereavement, offering excellent continuity of care that is highly valued by patients and their families.[452] The engagement of family physicians and general practitioners in palliative care varies widely: from less than 50% in some countries, such as Canada and Japan,[453,454] to up to 85% in the UK, the Netherlands, and Australia.[455–457]

The literature on the integration of primary palliative care into oncology is limited. As cancer care becomes more specialised, many family physicians lose contact with their patients for the duration of their cancer treatment; this loss of contact is often compounded by poor communication between cancer specialists and family physicians, making it challenging for family physicians to re-engage with patients at the end-of-life, or to recognise when patients are entering the final stages of their illness.[439,458,459] Other barriers to the provision of primary palliative care include time constraints,[171,460,461] insufficient reimbursement,[461] and insufficient palliative care training or expertise.[62,462] Out-of-hours support for community-based patients can be particularly challenging.[463] Home-based palliative care is often seen as labour intensive, poorly remunerated, and difficult to coordinate, especially outside of regular office hours, or when family physician offices are far from their patients' homes.[439,448,455]

Multiple initiatives have enabled the provision of primary palliative care, both among family physicians and in collaboration with secondary and tertiary palliative care providers. In some European countries (eg, Ireland, the Netherlands, the UK, and Denmark), out-of-hours cooperatives have been set up to lessen the burden on individual family physicians to provide round-the-clock care for their patients;[463,464] these cooperatives are generally well received by patients and practitioners alike.[465] Educational initiatives around the core skills of primary palliative care at the level of the medical student and postgraduate learner are vital, as are continuing medical education programmes, as discussed in the section of this Commission on education. The development of collaborative partnerships between primary and tertiary palliative care providers is recognised as a vital component of the promotion and support of primary palliative care,[448] as discussed later.

In the Netherlands, the general practitioner and home care nurse are the main providers of care for community-dwelling patients with cancer and palliative

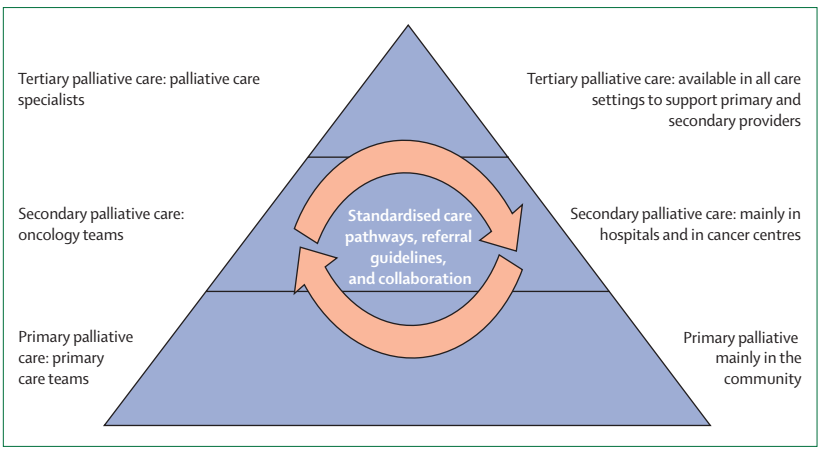


Figure 5: **Proposed model of optimal oncology palliative care provision, including integration across providers and settings**
Primary palliative care is community-based care provided by general practitioners, secondary palliative care is more complex care provided by oncologists, and tertiary palliative care is complex care provided by multidisciplinary specialist palliative care teams.

care needs. Over the past 10–15 years, nurse case managers have been introduced in some areas. To ensure continuity of care, the case manager collaborates with the patient, their informal carers, and the medical professionals involved in their care (ie, general practitioner and oncologist). The case manager provides advice to patients and their informal carers, and refers them to other care providers as necessary. The case manager might also offer palliative care advice to other health-care providers, including the general practitioner and the home care nurse.[466]

Secondary palliative care

Secondary palliative care refers to the care provided by the oncology team in the specialist health-care system to both inpatients and outpatients. Because oncology teams are based in hospitals and cancer centres for the most part, these are the main settings for secondary palliative care. Cancer care itself is multidisciplinary, and involves specialists from medical, radiation, and surgical oncology, as well as specialised nurses, social workers, psychologists, psychiatrists, dietitians, physiotherapists, and occupational therapists, among others.[467] All of these people require core clinical competencies in palliative care, as described later.

Important strides have been made in the promotion of secondary palliative care as a part of oncology care programmes. ASCO has formally endorsed early palliative care,[15] and has published several clinical guidelines for palliative care in oncology.[7,468] Several other international bodies have made efforts to formalise the role of oncologists in providing secondary palliative care. Among these efforts is a partnership between ASCO and the American Academy of Hospice and Palliative Medicine, which has produced a consensus statement using a Delphi process on high-quality palliative care delivery in US medical oncology practices[469] (panel 12). In this statement, they recommend that oncologists should provide regular systematic symptom assessment at least monthly, and a basic assessment of psychosocial wellbeing, faith group, and caregivers for distress if they accompany patients to the appointment.[469] Secondary palliative care also includes communication of prognosis to the patient and primary care provider, and assessment of prognostic understanding. Patients with complex or uncontrolled symptoms should be referred to tertiary palliative care services as available.[469]

Despite these guidelines, oncologists continue to vary in their perceptions of their role in providing secondary palliative care. Some provide no palliative care and refer all patients to tertiary services; some see themselves as solo providers of simultaneous oncology and palliative care, and do not refer to tertiary palliative care; and others refer to tertiary services only in complex clinical situations.[171] At the secondary palliative care level, patients might associate cancer treatment directly with hope, and a singular interest in pursuing active anticancer treatments can affect the delivery of appropriate palliative care.[176] An additional complicating factor might be that some patients prefer to receive more positive messages from their oncologist regarding their cancer, linking this with a greater compassion on the part of the physician.[470]

In an effort to improve integration and promote both secondary and tertiary palliative care provision, ESMO has developed designated centres of integrated oncology and palliative care on the basis of 13 rigorous criteria across clinical, research, and educational domains.[86] A 2017 survey of all active ESMO-designated centres identified high levels of routine symptom screening and goals of care discussions among oncologists, although less attention was paid to advance care planning and end-of-life discussions, which were more likely to be addressed by the palliative care services.[155]

Tertiary palliative care

Tertiary palliative care is provided by physicians and other multidisciplinary team members with specialist palliative care training. These teams might include specialised palliative care physicians, nurses, social workers, spiritual care providers, occupational and physical therapists, and pharmacists, among others. Clinical guidelines recommend that inpatients and outpatients with advanced cancer or high symptom burden, or both, should receive dedicated palliative care services early in the disease course concurrent with cancer treatment.[15] However, with shortages of tertiary palliative care specialists worldwide, limiting the provision of tertiary palliative care to the subset of patients whose care needs are the most complex and are not adequately met by primary or secondary level providers is more practicable. It is therefore important to have mechanisms to determine which patients would benefit most from consultation with tertiary palliative care services.[471]

Tertiary palliative care should be available to all patients with cancer, regardless of prognosis, and to primary and secondary palliative care providers on a consultant basis in all settings, including for inpatients, outpatients, and in the community. In settings in which resources are limited, palliative care services provide care mainly as consultation services for inpatients.[119] Acute palliative care units for the specialised management of complex symptoms and psychosocial concerns are limited to a minority of tertiary care hospitals and hospices.[438] In the community, long-term palliative care units, hospices, and palliative care home consultation services provide valuable support to patients at the end of life. Over the past few years, full integration, especially for patients at earlier stages of their illness, has been recognised as possible only through an outpatient palliative care programme.[35,171,472] Development or expansion of tertiary palliative care services should consider the unique needs, philosophy, and culture of the broader institution, with input sought from key stakeholders across clinical and managerial levels.[473]

Panel 12: **Essential elements of secondary palliative care in oncology practices**

Symptom assessment and management
- Monthly symptom assessment using a validated quantitative instrument
- Educate patients about the cause and management of existing symptoms
- Instruct patients how and when to contact the clinic during and after hours for new or worsening, or poorly controlled, symptoms
- Assess the effectiveness of adjusted medication by the next clinical encounter

Psychosocial assessment and management
- Conduct an initial, basic psychosocial assessment
- Assess distress with a validated quantitative instrument initially and after any clinical change (eg, cancer progression)
- Manage distress at a basic level with supportive, empathetic statements and validation of the patient's experience, otherwise patients should be referred

Spiritual and cultural assessment and management
- Document patient's faith
- Provide patients with a framework to consider their goals and hopes along with the probable medical outcomes of their illnesses and support those goals
- Assess and document preferences for communication and language
- Provide translation services

Communication and shared decision-making
- Assess patients and families for preferences for how they want to receive information regarding the patient's cancer, prognosis, treatment risks and benefits, treatment plan, and bad news, and who participates in the decision making and to what extent
- Provide oral and written documentation of the treatment plan to the patient and family, with specific details regarding expectations for disease control, effects on symptoms and quality of life, length and frequency of treatment, and the frequency of and rationale for disease reassessment
- Assess the patient's and family's understanding of the patient's illness, prognosis, and goals of care at diagnosis, disease progression, and with changes in the treatment plan
- Openly acknowledge and address mistakes as soon as they are noticed

Advance care planning
- Begin advance care planning at the diagnosis of advanced cancer, starting with assessing the patient's and family's readiness to discuss advance care planning and any concerns they might have
- Code status (ie, the type of resuscitation procedures requested by the patient), living wills, advanced directives, health-care surrogate, and out of hospital do not resuscitate orders should be discussed, completed and documented as soon as possible

Coordination and continuity of care
- Coordinate care with primary care, hospice, hospital, and nursing home

Appropriate palliative care and hospice referral
- Describe the difference between hospice and palliative care to patients and families as soon as possible after an advanced cancer diagnosis
- Conduct routine patient assessments to determine the need for palliative care or hospice referral
- Refer patients with a prognosis of 3 months or less, or an Eastern Cooperative Oncology Group performance status of 3–4 to hospice, or both
- Collaboratively agree on referrals with the patient or family, or both

Carer support
- Obtain permission to speak with primary caregivers and to include them in conversations about the patient's care
- Assess caregivers attending clinic visits with patients for distress at least once
- Inform caregivers how to contact the clinic in routine and emergency situations
- Provide information about local and online caregiver resources
- Provide bereavement follow-up in the form of a phone call or condolence card, or both, and information regarding local bereavement resources

End-of-life care
- Have processes to evaluate patient symptoms, advise medication changes to patients and family, and provide on-call coverage 24 h per day, 7 days per week

Panel adapted from Bickel and colleagues.[469]

How should tertiary palliative care be integrated?

Availability of tertiary palliative care for outpatients is of paramount importance for integration into standard oncology care, because most oncology care, including for patients with advanced disease, occurs on an outpatient basis. Several models of outpatient tertiary palliative care have been proposed, including mobile teams, free-standing palliative care clinics, and embedded clinics.[474,475] A mobile team, where outpatient palliative care consultations in oncology clinics are done by the inpatient consultation service on a same-day basis, is feasible if there are few consultations. However, outpatient palliative care clinics are more efficient on a larger scale, and allow patients to be seen by several multidisciplinary team members working together in the clinic.[472,476,477] The most robust evidence for early palliative care is for palliative care clinic interventions, and has shown that these clinics improve quality of life, symptom control, and mood.[3,5,63] Embedded clinics offer opportunities for oncologists and palliative care clinicians to collaborate and coordinate care, and allow rapid access to palliative care teams. However, this model presents challenges,

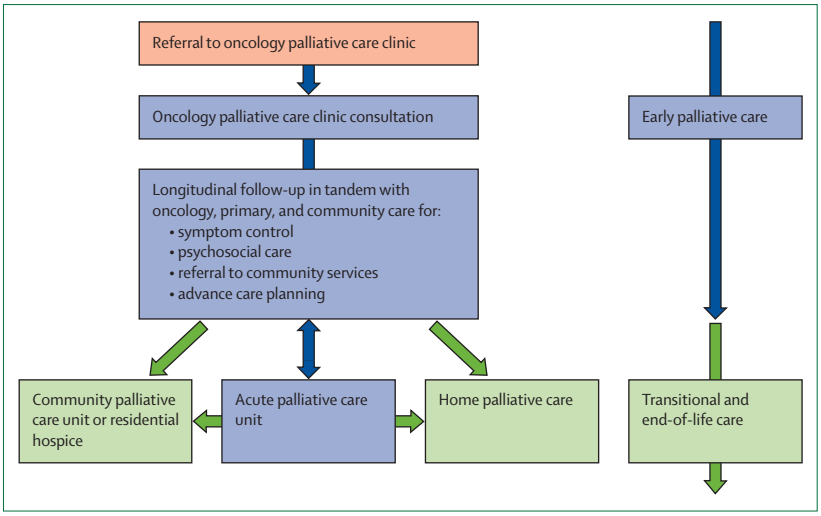


Figure 6: **Tertiary palliative care on the basis of referral to a palliative care clinic**
Referrals are made by the patient's oncologist. Care is integrated and collaborative across acute and community care settings. Ultimately, care is transferred to home, hospice, or a palliative care unit. Figure adapted from Hannon and colleagues.[472]

including finding adequate clinic space, fatigue on the part of patients with longer clinic visits, and involvement of only one discipline—usually a single physician or nurse.[148]

Several models of integrated tertiary palliative care programmes have been described. In 1995, the palliative care programme in Edmonton, Canada, was one of the first to report their practice, which consisted of an inpatient palliative care unit housed within an acute hospital setting, as well as a consultation service and an outpatient clinic. From the outset, a strong emphasis was placed on the use of standardised assessment tools, wide-ranging education and research initiatives, and close integration with family physicians to enhance primary palliative care provision.[478,479] These elements of care were similarly emphasised in subsequent reports of successful tertiary palliative care programmes in Lausanne,[480] Milan,[481] Cleveland,[482] Houston,[483] Trondheim,[47] and Toronto,[484] with the Trondheim and Toronto programmes also publishing successful randomised controlled trials illustrating the effectiveness of this model of care.[5,47] The model of palliative care at the Princess Margaret Cancer Centre, Canada, serves as one empirical example and is described in figure 6.

Barriers to integration of tertiary palliative care

Several areas are consistently identified as barriers to fully integrated oncology and palliative care services, across system, organisational, and clinical levels. An absence of institutional recognition of the value of tertiary palliative care services has limited the development of new services. Palliative care services are infrequently afforded the same priority as other areas of cancer detection and treatment at executive or managerial levels. A new initiative from the Union for International Cancer Control aims to address this issue, identifying palliative and supportive care as one of the four essential pillars of cancer treatment and care (along with cancer data for public health, early detection and diagnosis, and timely and accurate treatment).[485] ESMO-designated centres also strive to boost the status of integrating high-quality palliative care services within oncology.[438,486]

Closely connected to this is the problem of adequate funding to support integration. Although oncology leadership tends to agree that integration is beneficial, funding to support programme expansion often lags behind. A survey of members of the Multinational Association of Supportive Care in Cancer, the European Association for Palliative Care, and ESMO found that only 17% of respondents felt their institution was likely to increase palliative care funding; 49% felt it was unlikely their institution would increase inpatient palliative care beds; and respondents were neutral regarding future palliative care team hiring plans.[438] Despite several studies[137] demonstrating the cost-effectiveness of palliative care teams, cost-effectiveness does not seem to factor into budgetary considerations at the oncology level.

A shortage of trained medical and nursing personnel, and poor reimbursement for palliative care physicians have also been cited as barriers to the access and development of tertiary palliative care, even within cancer centres and ESMO-designated centres of integrated oncology and palliative care.[438] At the individual oncologist level, substantial heterogeneity remains in referral practices to tertiary palliative care teams because of factors ranging from personal opinions to structural issues. For some oncologists practising secondary palliative care, especially in community practice, the additional reimbursement afforded by this might limit their willingness to fully integrate with palliative care teams or refer to tertiary palliative care services.[438] In an effort to standardise referral practices, the use of specific criteria to trigger automatic referral to palliative care teams alongside concurrent oncology care have been proposed; the success of these criteria has yet to be explored.[35]

Ongoing stigma and misconceptions about the term palliative care are frequently quoted as barriers to integrated services.[487] Because of its historical association with end-of-life care and medical futility, the name itself is often cited by oncologists and patients as an obstacle to early referral[164] (see the section of this Commission on societal challenges). In one centre, the outpatient palliative care service has been renamed supportive care, which has been associated with earlier referrals.[488]

Human resources and clinical competencies

To deliver high-quality, integrated palliative care, an interdisciplinary approach is required. The competence of palliative care needs to be placed into context in the cancer plans, such as participation in the multidisciplinary teams as active and integrated partners. As mentioned

earlier, the multidisciplinary team includes not only physicians and nurses, but also social workers, spiritual care providers, physiotherapists, occupational therapists, psychologists, psychiatrists, and pharmacists, among others. Inclusion of these skills can be provided by the palliative care specialist physician, on the basis of the needs addressed by the multidisciplinary teams. Access to and close links with community-based nursing and allied health-care providers is also essential to ensure seamless transitions between care settings.

In terms of clinical competencies, primary palliative care providers should have core skills in assessing and managing physical and psychological symptoms, as well as knowledge to use SDM in daily clinical practice, which also includes ACP for patients with short life expectancy and planning, coordinating, and providing end-of-life care in patients' homes when feasible.

Core teaching on pain and symptom management, and end-of-life care has been recommended for medical students in the UK and the USA;[489,490] initiatives such as the Canadian Learning Essential Approaches to Palliative and End-of-life Care (LEAP) programme provide multidisciplinary primary palliative care training for all health-care providers (see the section of this Commission on the role of education).

For secondary palliative care, wide variations exist in terms of the training and competencies of individual oncologists, which is often a result of the clinical setting within which they work. Many physicians working within designated centres of integrated oncology and palliative care are dual-certified in both oncology and palliative care (65% in a 2017 study).[155] These centres were also more likely to have access to a broad range of multidisciplinary clinicians.[155] Mandatory rotations in palliative care and modules in symptom management, communication skills, and updated skills in SDM and ACP have been recommended to improve secondary palliative care competencies. At minimum, competencies should include basic assessment of pain and other symptoms; assessment of psychosocial, spiritual, and cultural needs for the patient and family; appropriate goal-based communication; skills in using SDM and ACP; and coordination of end-of-life care.

Tertiary palliative care services should be led by clinicians with specialist palliative care training and certification where available. As of today, most countries with such a certification have organised it as a dual certification. For cancer centres, specialist certification in both oncology and palliative medicine is necessary (see the section of this Commision on education). As consultants, these clinicians should have appropriate training in the management of complex symptoms and problems throughout the disease course and bereavement. Palliative care is now recognised as a medical specialty or subspecialty across 18 European countries as well as the USA, Canada, and Australia.[491]

Care transitions and collaboration: moving among levels of care

Several common facilitators to successful integration across primary, secondary, and tertiary palliative care have emerged, including structures and tools for transitions between levels of care and collaboration among disciplines. Although there might be some overlap of roles, clarity and clear division of each team's respective responsibilities is necessary to ensure a consistent message for patients.[171,492,493]

Referral guidelines or other types of predefined structures, such as palliative care incorporated in the SCP in detail, can help to clarify which patients and when these patients are likely to benefit from referral to tertiary palliative care services. In a recent study[471] using a Delphi process, international palliative care experts reached consensus on 11 major criteria for outpatient palliative care referral in cancer centres, on the basis of stage of disease, prognosis, and clinical problems. These criteria were categorised into needs-based and time-based criteria (panel 13).[471] The palliative care experts reached consensus on referrals based on both automatic referral and clinician-based referral, with only 7% agreeing that referral should be based on automatic referral alone.[494] These criteria can be used as guides when detailed SCPs are developed in oncology.

SCPs have been suggested as a potential means of recognising transition points in care and ensuring high-quality care regardless of the clinical setting. In Canada, Cancer Care Ontario has developed collaborative care plans based on Palliative Performance Status (PPS) for stable (PPS 70–100), transitional (PPS 40–60), and end-of-life (PPS 0–30) stages. Lessons learned from the use of SCPs in end-of-life settings indicate that these

For the **Canadian Learning Essential Approaches to Palliative and End-of-life Care (LEAP) programme** see http://pallium.ca/

***Panel 13:* Models of palliative care integration**

Needs-based

- Severe physical symptoms (eg, pain, dyspnoea, or nausea scored 7–10 on a ten-point scale)
- Severe emotional symptoms (eg, depression, or anxiety scored 7–10 on a ten-point scale)
- Request for hastened death
- Spiritual or existential crisis
- Assistance with decision making or care planning
- Patient request
- Delirium
- Brain or leptomeningeal metastases
- Spinal cord or cauda equina compression

Time-based

- Within 3 months of diagnosis of advanced or incurable cancer for patients with median survival of 1 year or less
- Diagnosis of advanced cancer with progressive disease despite second-line systemic therapy (incurable)

Panel adapted from Hui and colleagues.[471]

Panel 14: **Models of integration—recommendations**

- Establish integrated specialised palliative care or oncology services, or both, at cancer centres by developing integrated models, training personnel, making palliative care mandatory at the multidisciplinary teams, and giving economic incentives
- Establish multidisciplinary community teams for early integration by developing models for community teams and evaluating the models in research projects
- Integrate community-based and hospital-based services by establishing formal contracts on integration and payment plans (resource setting)
- Embed basic early palliative care into oncology programmes by making palliative care a mandatory part of oncology training, and revising national content of oncology training programmes and give international recommendations

pathways should be detailed while also flexible in addressing individual needs; not be a substitute for empathic care of the patient; and be coupled with ACP, comprehensive education, and training in palliative care.[495,496] Further research is needed to assess the effectiveness of these pathways in earlier stages of disease.[187,497]

The development of strong, collaborative relationships among primary, secondary, and tertiary providers are essential for truly integrated care. Among primary and tertiary palliative care providers, strategies could include mentorship and advisory programmes facilitating ready access to tertiary palliative care teams, including out-of-hours support; inviting primary palliative care providers to engage in discharge planning discussions or family meetings for shared patients before home discharge; and maintaining excellent communication between community-based and hospital-based teams through shared electronic records. These partnerships could help to improve family physicians' confidence in providing primary palliative care and in recognising transitions in care.[448]

Collaboration between secondary and tertiary palliative care providers in cancer centres should be a part of the multidisciplinary teams, encouraged by joint rounds and tumour boards, and supported by combined palliative care and oncology educational activities for trainees.[44] Shared support staff (eg, allied health professionals or nursing staff) can act as a bridge between services.[171,493] Joint patient consultations, proximity of palliative care clinics to oncology clinics (or palliative care clinics embedded into oncology clinics), and the involvement of palliative care teams in tumour boards or cancer committee meetings might be superior to communication via email or phone.[171,492] In addition to the clinical advantages offered by such collaborative models, there are also potential financial advantages associated with pooling resources, especially in the early stages of palliative care programme development.

Collaboration can also be facilitated by technology and clinical tools. Symptom screening has been established as a standard of care in all cancer centres in Ontario, Canada,[498] and proven to be effective in routine oncology practice[75,499] and in pilot projects in primary care practices.[500] This collaboration can serve to encourage systematic assessment and management of symptoms by oncologists, and trigger timely referral to tertiary palliative care programmes. Joint electronic patient records or mutual access to patient records, among all levels of care providers, can improve information transfer among care providers in the hospital and community.[501] Telehealth is also being explored as an intervention to improve communication in palliative care, particularly for people living in rural regions.[502]

Conclusion

We have presented conceptual models of palliative care integration, as well as principles, competencies, and resources necessary to achieve integration in various settings. There is no single model of palliative care integration that is tested in clinical studies or used in all health-care systems. This heterogeneity can indicate that palliative care integrated in oncology is in its infancy. The need to agree, on the basis of high-quality studies, on models that fit the different health-care systems in countries of high and middle income is urgent. The overall goals of such a discussion are that these novel organisational models will meet the needs of all patients in all settings and circumstances. However, a successful model of integration needs to incorporate primary, secondary, and tertiary providers; span the inpatient, outpatient, and community settings; and specify how movement between these levels occurs in a systematic fashion. Although sound evidence exists for the involvement of early tertiary palliative care for patients with advanced cancer, little exists for models of primary and secondary palliative care provision, and for care pathways bridging levels of palliative care. Research in these areas should be prioritised. Recommendations are presented in panel 14.

The role of education: challenges and recommendations

Several of the previous sections have highlighted the need for education of health-care providers as a key factor for the promotion of integration of oncology and palliative care, both on the clinical and organisational levels. This is in line with recommendations from experts, stakeholders, and professional health organisations.[44,503,504] At present, the need for basic and specialist competence in palliative care is unmet at all levels of health care, which calls for increased educational efforts.

Integration of oncology and palliative care requires close collaboration and exchange of information between

primary, secondary, and tertiary palliative care providers (see the section of this Commission on models). Tertiary palliative care specialists are often located in comprehensive cancer centres or university hospitals, and are commonly also engaged in academic activities such as research and education. The skill set of tertiary palliative care specialists is essential to support primary and secondary providers. These premises expand the responsibilities of tertiary palliative care beyond the cancer centre setting through education and mentorship programmes aiming to upskill primary and secondary health-care providers.

The heterogeneity of the organisational models described in the section of this Commission on models does not allow for conclusions to be drawn about the kinds of competence and skills that best promote integration. We were unable to identify reports, policy statements, or articles at an international level that specifically addressed how education programmes can promote integration of oncology and palliative care, or what they should include, except for general statements about palliative care.

In this section, we therefore describe available international educational strategies and recommendations in palliative care, contents of oncology and palliative care curricula, and educational barriers and facilitators. We also discuss how education can promote integrational models. Medical education from undergraduate to postgraduate levels is the primary focus of this section, with the awareness that palliative care shall be delivered by multidisciplinary teams that include health-care providers with qualifications in disciplines other than medicine. Expanding the panel to the education of all the other important health-care providers in the multidisciplinary team would exceed the limits of this section. With a focus on medical education, principles and content are also considered of value for education of other health-care providers.

This section is based on available information on palliative care education (specialisation and postgraduation programmes), such as the supplement to the EAPC Atlas of Palliative Care in Europe,[491] EAPC Atlas of Palliative Care in Latin America,[505] and the website Global Directory of Education in Palliative Care of the IAHPC.[506] Further information was gathered from medical society papers, websites supplemented by a systematic review of literature using the MESH terms palliative or palliation, oncology or cancer, and education, and the words integration or integrative in the title or abstract. The search yielded 23 articles considered of relevance for this section. Of those articles, 12 were informative articles (consensus, panels, indicators, recommendations, discussion, debate, or state-of-art) regarding integration of palliative care and oncology); four were descriptions or evaluations of multidisciplinary curriculum or specialist education, four presented professional perspectives or opinions, two surveys focused on guidelines and service management, and one was a systematic review about early integration.

Panel 15: **Three levels of palliative care**

Basic
(Level A; undergraduate and postgraduate)
Integrate palliative care methods and procedures in general care, for all health-care professionals

Advanced
(Level B; postgraduate)
For professionals involved with palliative care, but not as their main occupation (eg, oncologists)

Specialist
(Level C; postgraduate)
For professionals working solely in palliative care whose main activity is complex problems requiring specialised skills and competencies

Educational strategies

International agencies and professional associations have developed and promoted policies and projects, including educational strategies and recommendations, to improve palliative cancer care. WHO has recognised that national actions are necessary to strengthen palliative care education, and that such action should be "ensuring that education about palliative care (including ethical aspects) is offered to students in undergraduate medical and nursing schools and health care providers at all levels, in accordance with their roles and responsibilities and as part of human resource development". EAPC has launched a recommendation of three levels of palliative care education that can serve as a basis for integration[507,508] (panel 15). Another example of an integrative approach originates from ESMO, which has developed designated centres of integrated oncology and palliative care on the basis of rigorous criteria across clinical, research, and educational domains, promoting both secondary and tertiary palliative care provision. To date, close to 200 centres from 41 countries have achieved this designation.

Accreditation of palliative medicine

In general, certification in palliative medicine falls into three categories, depending on the postgraduate educational system of the different countries: specialty, subspecialty, and general competence in the field. All three categories require a basic medical degree; however, subspecialty in palliative medicine also requires a clinical specialty degree in another medical area. Certificate of competence refers to formal educational courses in palliative medicine approved by national health authorities and medical societies, but not necessarily a recognised new specialty in some countries.[491] The supplement of the EAPC Atlas of Palliative Care in

	Accreditation	Denomination in English	Clinical practice (years)	Theoretical training	Research
Australia and New Zealand	Specialty	Palliative medicine (medical specialty)	3	..	One to three projects
Canada	Subspecialty	Subspecialty of palliative medicine	2	350 h	One project
Czech Republic	Subspecialty	Palliative medicine	1	12 months	..
Denmark	Special denomination	Competence in the field of palliative medicine	2	6 weeks	One project
Finland	Special denomination	Special competence in palliative medicine	2	150–270h	One project
France	Special denomination	Diploma of complementary specialised studies in pain medicine and palliative medicine	2	170 h	One project
Georgia	Subspecialty	Palliative care and pain medicine	0·5	75 h	..
Germany	Subspecialty	Palliative medicine	1	40 h	Not required
Hungary	Subspecialty	Subspecialty in palliative medicine	1	80 h	..
Ireland	Specialty	Certificate of completion of training as specialist in palliative medicine	4	Varying between different universities	Not required
Israel	Subspecialty	Palliative medicine subspecialty	2	..	..
Italy	Special denomination	Master's programme in palliative care for specialist physicians	0·5	1500 h	One project
Latvia	Special denomination	Special competence in palliative care	2	400 h	80 h
Malta	Specialty	Palliative medicine	Most training acquired abroad	Most training acquired abroad	Not required
Norway	Special denomination	The formal competence field of palliative medicine	2	180 h	One project
Poland	Specialty	Specialisation programme in palliative medicine for physicians	2	..	One project
Portugal	Special denomination	Palliative medicine competence	1	400 h	Three projects
Romania	Subspecialty	Diploma of complementary studies in palliative care	0·25	2 months	..
Slovakia	Special denomination	Specialisation study in the field of palliative medicine	0·5	..	..
Sweden	Subspecialty	Subspecialty in palliative medicine	2·5	120 h	Not required
UK	Specialty	Certificate of completion of training as specialist in palliative medicine	4	Varying between the different universities	Not required
USA	Subspecialty	Hospice and palliative medicine certification	1	Varying between the different universities and states	Varying between the different universities and states

Table adapted from Bolognesi and colleagues[509] and Centeno and colleagues.[510]

Table 6: **Accreditation of palliative medicine education**

Europe[491] collected information on education and certification in palliative care from 18 European countries, Australia, Canada, and the USA. As expected, type of certificates, demand for clinical practice, theoretical content and length, and whether research was a mandatory component all varied (table 6).

The integration of palliative care into oncology might be highly dependent on the level of accreditation. Thus, the different models of integration generally originate from countries with some kind of accreditation of palliative medicine and availability of tertiary palliative care. Palliative medicine achieved specialty or subspecialty status in the UK in 1987, the USA in 2006, and Canada in 2016.[511,512] Palliative medicine has also been established as a specialty in multiple countries in the Asia-Pacific region, including Australia, New Zealand, China, Japan, Taiwan, Malaysia, Singapore, and India.[513] Other countries in Europe, Asia, Latin America, and Africa are actively working toward accreditation. In some countries, such as the UK, Ireland, New Zealand, and Australia, palliative care is a full medical specialty, requiring a minimum of 3 to 4 years of postgraduate training to achieve certification. In other countries (eg, Canada, the USA, France, and Germany), palliative care is organised as a medical subspecialty.[514,515] Other educational programmes are directed towards medical specialists associated with some kind of accreditation, which include the Japanese Palliative Care Emphasis Program on Symptom Management and Assessment for Continuous Medical Education (PEACE)[515,516] and The Nordic Specialist Course in Palliative Medicine.[517] The Nordic Specialist Course in Palliative Medicine is a joint venture between the Associations for Palliative Medicine in the Nordic countries (Denmark, Sweden, Norway, Finland, and Iceland), and has resulted in a theoretical specialist training course in six modules over 2 years, combined with a clinical stay at a specialised palliative care unit. However, palliative medicine was accredited as a special competence in Finland in 2007, and a subspeciality in Sweden in 2015.[491]

The heterogeneity in specialty status without clearly defined competencies for palliative care physicians is

probably associated with variability in the content and quality of care delivered, and is a challenge for the advancement of clinical palliative care. Furthermore, the classification and definitions of speciality and subspeciality differ considerably between countries, as can be seen from the clinical practice and theoretical training section of table 6. A substantial proportion of those attending the programmes are oncologists who have been recruited for the subspecialty model for palliative medicine, which might enhance integration.

Palliative care and oncology curricula for physicians

Several documents specify a framework for competence for physicians, developed by their respective national medical associations. Our literature review showed that education in palliative medicine is generally recommended to be included in undergraduate and postgraduate curricula, updated by continuing education, lectures, courses, and conferences. The EAPC Steering Group on Medical Education and Training published prototypes of postgraduate and undergraduate curricula for palliative medicine in 2009, and 2013.[518,519] In addition, rotation of trainees and fellows is common, and is designed to promote integration[35,148,468,508] (table 7). Thus, curricula in palliative medicine might facilitate integration of oncology and palliative care from an early stage in the education process.[520] EAPC recommends curricula at medical schools should cover six domains, achieving six overall learning goals.[520] Recommended educational goals include experiential learning, active techniques, multiprofessional learning, and experience in palliative care, and must cover more than 40 hours in total. The topics should be included in examinations, teaching should be done by palliative care specialists and professional groups other than doctors (eg, nurses, psychologist, and chaplains), and ethical and, psychological social, and existential issues should be integrated into the curricula. Additionally, education in palliative care should be removed from oncology and anaesthesiology, and taught as an independent subject.

Bolognesi's survey[509] addressed various subjects present in the postgraduate palliative care specialisation programmes in Europe, including pain and symptom management, pharmacology of opioids and other essential drugs, psychosocial issues, ethical issues, communication, teamwork, organisation of delivery of care, end-of-life care, normative and legal issues, oncology, non-malignant diseases, supplement by community palliative care, culture, language and religion, grief and bereavement, and applied teaching from other disciplines, including radiology, psychiatry, and public health. Specialist palliative care curricula should provide sufficient theoretical and practical knowledge and skills to handle oncological emergencies, including clinical detection, emergency management and referral to specialists for spinal cord compression (eg, radiotherapy and neurosurgery), pathological fractures, raised intracranial pressure, superior vena cava obstruction, and hypercalcaemia. Knowledge about prognostication of different cancer diseases, chemotherapy lines, and radiation therapy should also be implemented in the curricula. At present, no overall recommendations on the exact amount of oncological teaching in postgraduate palliative care accreditation programmes exist, and the actual amount is probably highly variable in different countries.

ASCO have deliberately included current best evidence of palliative care in oncology curricula, aimed at enhancing oncologists' understanding of the basic principles of palliative care, while acknowledging that complex scenarios and refractory suffering should be referred to palliative medicine specialists.[15] The third edition of the Recommendations for a Global Core Curriculum in Medical Oncology, published in 2004, and updated in 2010, and 2016,[521] outlined specific competencies for oncologists related to supportive and palliative care and was endorsed by ASCO and ESMO (panel 16). At present, no overall data on the amount of palliative care teaching in postgraduate oncological

	Levy et al (2014)[468]	Gamondi et al (2013)[508]	Hui et al (2015);[44] Hui and Bruera (2015, 2016)[35,148]
Palliative care in undergraduate curricula	Y	Y	Y
Lectures and curricula on palliative care for oncology professionals	Y	..	Y
Oncology rotations for palliative care fellows	Y	..	Y
Palliative care rotations for oncology fellows	..	..	Y
Conferences on palliative care for professionals	Y	..	Y
Continuation education for practicing oncology professionals	Y	Y	Y
Palliative care skills formal examinations	Y	..	Y
Combined palliative care and oncological educational activities for fellows and trainees	..	..	Y
Post-graduation in palliative care	..	Y	Y

Y=strategy suggested.

Table 7: **Suggested educational strategies to improve competences**

Panel 16: **Main objectives of the recommendations for a global core curriculum in medical oncology**

- To screen, assess, prevent, and manage symptoms of patients with cancer such as pain, fatigue, anorexia, anxiety, depression, breathlessness, and nausea
- To communicate effectively with patients and families about understanding of and coping with cancer, prognosis, difficult decisions, end-of-life and its preparation, including psychosocial and existential dimensions
- To recognise the role of cancer rehabilitation, including physical therapy and nutrition
- To recognise the importance of culturally competent, multidisciplinary care that also includes the families
- To understand how to integrate palliative interventions in routine multidisciplinary cancer care
- To recognise the difference between burnout, compassion fatigue, and depression
- To ensure timely referral to specialist palliative care teams

accreditation programmes exist, and the actual amount is probably highly variable in different countries.

The NCI has developed the Education in Palliative and End-of-Life Care for Oncology (EPEC-CO) curriculum—a multimedia curriculum that can be used as a self-study tool or presented by seminar or webinar.[522] The Northwestern University Feinberg School of Medicine offers the train-the-trainer EPEC courses to facilitate dissemination of the curriculum via certified EPEC trainers.[523] The Accreditation Council for Graduate Medical Training in the USA has also mandated competency in hospice and palliative care for medical and haematological oncology fellowship programmes.[461]

In addition, educational curricula have been organised as the LEAP and LEAP Oncology programme and the Virtual Learning Collaborative, a web-based education module under development by ASCO and American Academy of Hospice and Palliative Medicine.[524] Moreover, US and European organisations, such as the National Comprehensive Cancer Network (NCCN) and ESMO, have published clinical practice guidelines on palliative care.[325,468,525,526] These initiatives are a step towards the integration processes. Moreover, an international Delphi survey[44] identified four major educational strategies related to postgraduate oncology programmes: a didactic palliative care curriculum for oncology fellows provided by palliative care teams, continuing medical education in palliative care for attending oncologists, combined palliative care and oncological educational activities for fellows and trainees, and routine rotation in palliative care for oncology fellows.[148]

The heterogeneity in education programmes (ie, the competence defined as needed in palliative care) probably mirrors the heterogeneity in organisation and in what is delivered in clinical palliative care across, and maybe even within, countries. The present recommendations have similarities, but perhaps what is more striking is the broad scope introduced by the variation in programmes across countries.

Educational barriers to, and facilitators of, integration of palliative care and oncology

Lack of education and training, and the common perception of palliative care as being end-of-life care only, have been identified in different settings.[148,503,504,527,528] A 2016 review, stated that education (in addition to policy and implementation) is a key barrier to palliative care integration in the USA.[527] The education barrier is both of quantitative and qualitative nature. The quantitative aspect includes the insufficient numbers of health-care workers with adequate training and education to provide
palliative care at their level in the health-care system, which is not confined to US settings. The qualitative aspect includes the large variations in content across countries regarding both undergraduate and post-graduate education and training.

These workforce-related issues are substantial barriers because palliative medicine is the fastest growing medical specialty or subspecialty worldwide.[529] These issues are not only related to low staffing levels, but also to the level of competences and practical skills, inadequate training in communication, insufficient knowledge about the quality of the health-care delivered by other professions or specialists, and resistance to refer patients to specialised palliative care or hospices.[444,530,531] Therefore, expansion and support of educational programmes for newly educated and midcareer physicians are crucial to meet the workforce shortage in palliative medicine.[527]

Although proposals exist on how to develop and enlarge the contents of curricula for oncologists and for palliative care specialists at different levels of specialist education, budget constraints and absence of administrative support can hamper the development of educational and training programmes intended to enhance integration. Despite the fact that Europe is considered the pioneer region of palliative care, a descriptive EAPC study[532] of undergraduate medical education in Europe (43 countries) identified low investments in education. Palliative medicine was taught in medical schools in only 13 (30%) countries and was a compulsory course in six (14%) countries, with only 17 (40%) countries having a full professorship in palliative medicine.[532] The study did not explore the reasons for these low numbers. Knowledge of oncology and palliative care congruent with the level of care that is given constitute the underlying premise for integration of palliative care and oncology. Thus, this knowledge must be compulsory in all curricula from undergraduate to postgraduate and specialist education programmes.

In a 2016 study exploring attitudes and beliefs among oncology trainees regarding palliative care, 67% believed a mandatory palliative care rotation was important; those who had completed palliative care rotations were more aware of the role of palliative care services than those who had not done so (96% *vs* 74%).[533] A survey of Canadian oncologists found that oncologists were more likely to refer to tertiary palliative care services when they had completed a rotation in palliative care.[164] Thus, being part of a larger, multidisciplinary team alongside palliative care colleagues allows oncologists to share the burden of complex care delivery, potentially also preventing burnout and compassion fatigue.[163] Oncologists' willingness to engage with palliative care services correlates positively with self-reported comfort around managing end-of-life issues.[174]

The integration of oncology and palliative care should be a two-way street. A clinical rotation is essential for integration of these disciplines, because it could help oncology fellows to acquire knowledge of the basic principles of symptom management and communication, understand when referral is appropriate, and build a working and research relationship with the palliative care team. A rotation could also help to destigmatise palliative care, and might result in increased interest among

oncologists for subspecialisation in palliative oncology. The latter subspecialisation could enhance recruitment to an emerging discipline. Because many palliative care specialists have a background other than oncology, clinical rotation the other way round (ie, to oncology) is also warranted. Similar to the way in which patient care might be improved by education of oncologists in palliative care, rotations in medical and radiation oncology could be of benefit for palliative care fellows, to increase their familiarity with the natural history of cancer, cancer treatment modalities, and the complex decision-making process surrounding cancer treatment at the end of life. Such rotations might also help palliative care specialists and oncologists nurture a mutual understanding, strengthen their partnerships, develop common clinical pathways for their patients, and enhance research collaboration.

To ensure and justify the investments in the integration of oncology and palliative care, the effectiveness of different teaching methods in palliative care education and the benefits of single-profession and multiprofession education should be studied. The effect of how education and training programmes on treatment, patient care, and organisational issues (eg, care, economy, and collaboration) needs to be documented, and the delivery and effects of undergraduate and postgraduate education on the promotion of palliative care integration mapped. Health-care organisations increasingly require evidence of the effect of education, so a robust evidence base to justify the cost and time of delivering education in palliative care must be established.

Tertiary palliative care specialists are often located in comprehensive cancer centres or university hospitals, and are also commonly engaged in academic activities. Leveraging of the skill-set of tertiary palliative care specialists to support primary and secondary providers of palliative care, and expansion of the scope of tertiary palliative care beyond the cancer centre setting, through education and mentorship programmes, might help to upskill primary and secondary providers and clarify the respective roles of each. Tertiary palliative care specialists working in comprehensive cancer centres or in close conjunction with oncological departments must have skills and competence in oncology. Although the level of skill needed by these specialists has not yet been made concrete, they should have the skills and knowledge to handle oncological emergencies, prognosticate different cancer diseases, and about chemotherapy and radiation therapy to enable them to cooperate with the oncologist in deciding the optimal treatment proposal for each patient.

Education programmes in palliative medicine are highly heterogeneous at all levels of health care, and across countries and perhaps also within regions. This heterogeneity is, in itself, a substantial barrier for further integration of oncology and palliative care. One might speculate whether this heterogeneity is related to the immaturity of palliative care as a medical specialty, the absence of recognition of the added value of including palliative care in the standard treatment lines, financial issues, difference in scope, or difference in focus (ie, the tumour versus the host) between oncology and palliative medicine. In line with others,[315] we think a shift of the paradigm towards models based on patient-centred care is highly warranted at all levels, and education programmes should reflect this shift. Patient-centred care does not exclude targeting the tumour, but instead uses a combined approach—the tumour and the host. This combined approach is a focus that needs to be taught. In our view, the strive to include the patient in education and practice is a general challenge of contemporary medicine. Models such as shared decision-making are available, but these are still strangers to most medical curricula.

Communication skills are essential to provide patient-centred care. For patients with advanced cancer, the patient-centred approach is of pivotal importance to ensure best possible care, whether oncological or palliative. Training and education to improve physician-patient communication as part of patient-centred education programmes should, therefore, be emphasised in curricula across different specialisations. Communication must be learnt; thus, it must be taught as part of all curricula in basic, intermediate, and specialist medical education. Oncologists and palliative care specialists should receive specific communication training regularly to maintain and develop their skills, and to share fundamental skills.[326,403] Several methods are available for teaching communication to clinicians; communication skills training with role play and feedback, e-learning, group discussions, modelling, case evaluations, and coaching are some of the most commonly used strategies. Overall, strategies that are active and involve practice seem to be most efficient.[406] Recommendations are presented in panel 17.

Panel 17: **The role of education—recommendations**

- Ensure palliative medicine is accredited as a specialty or subspecialty in all countries by encouraging public awareness of the needs and national and international recommendations of accreditation, and adapting the accreditation from successful countries
- Ensure mandatory teaching of palliative care subjects in medical, radiation, clinical and surgical oncology specialisation programmes
- Develop a set of minimum volume and content requirements for use in these programmes, including mandatory clinical rotation in palliative care
- Develop international teaching programmes on when and how to integrate oncology and palliative care by requiring programme development at the level of the health-care provider and from professional organisations (eg, European Society for Medical Oncology, European Association for Palliative Care, European Society for Radiotherapy and Oncology, American Society for Radiation Oncology, and American Society of Clinical Oncology), and applying indicators for programme development and implementation
- Encourage continuous education of multidisciplinary teams in early integration and in teamwork by requiring education for oncologists and palliative medicine specialists in patient-centred care and early integration

Research

With increasing integration of oncology and palliative care, specialist palliative care is no longer only involved in the last days and weeks of life, but throughout the disease journey—from the time of diagnosis of advanced cancer. Patients are often concurrently managed by the oncology and palliative care teams, creating ample opportunities for collaborative research to improve patient care.

	Opportunities	Challenges
1	Sharing of clinical and research expertise	Need time to communicate and build the trust and relationship between teams
2	Access to patients (eg, enrolling patients from oncology clinic to assess palliative care needs)	Potential conflicts between teams because of differences in approaches
3	Opportunities for new areas of research and discoveries at the interface of disciplines (eg, defining roles and responsibilities for delivery of palliative care by oncologists)	Potential competition for study leadership
4	Sharing of work (eg, expertise) and resources (eg, staffing) might reduce overall cost	More resources might be needed to allow larger research teams

Table 8: **Opportunities and challenges for integrating oncology and palliative care teams to do research**

***Panel 18:* Research opportunities related to integration of palliative care and oncology—recommendations of future research questions**

Specialist palliative care referral

- What is the optimal timing for palliative care referral (eg, resource-rich *vs* resource-poor settings, large *vs* community hospitals, and cancer *vs* non-cancer)?
- Should time-based or need-based criteria be driving palliative care referral?
- Can standardised referral criteria coupled with automatic referral streamline the referral process?
- What strategies can help to overcome barriers to referral among patients and oncologists?
- What is the effect of palliative care intervention on patients' ability to complete cancer treatments?
- What is the role of palliative care for patients with curable cancer?

Palliative care programmes

- What is the standard (minimum requirement) for a palliative care programme in different health-care settings?
- What are the advantages and disadvantages of various novel models (eg, palliative care teams involved in multidisciplinary tumour boards or embedded clinics)?
- What should be the metrics or benchmarks to measure the success of a hospital, region, or nation on palliative care delivery?
- How can a clinical practice guideline on palliative care be developed and used to inform practice?
- How can primary care teams integrate to provide palliative care?

Education

- How much palliative care do oncologists need to know to deliver effective palliative care?
- How much oncology do palliative care specialists need to know to deliver effective care?
- What are the most effective strategies to educate oncologists about palliative care?
- How can the training and accreditation for specialist palliative care be standardised in different countries?

Public policy

- What public policies are most effective to drive palliative care?
- What are some strategies that professional organisations can adopt to support integration?
- How can investment in palliative care programmes be optimised to maximise the value of health-care expenditure?

In this section, we will focus our discussion on three major areas of research parallel to increased integration between oncology and palliative care: system-oriented health services studies to examine different models of care, and understand the optimal processes and outcomes of improved integration of oncology and palliative care; patient-centred research to examine physical symptoms, psychosocial distress, communication, and decision-making preferences throughout the disease trajectory; and public health-oriented research to examine external validity of the integration of palliative care and oncology in the whole society (eg, a region or a country), and to develop and evaluate societal implementation strategies. Some of the opportunities and challenges to integration of palliative care and oncology that would benefit from research attention are highlighted in table 8.

Opportunities for system-oriented research

A growing number of studies have addressed potential benefits of early integration of palliative care in oncology.[3,5,47–51] The question is no longer whether patients would benefit from palliative care, but how palliative care oncology teams need to provide care, when is the optimal timing for referral to specialist palliative care, how comprehensive do the palliative care teams need to be, and what is the minimum model for care delivery. A 2016 Delphi study[471] identified 11 major criteria to refer patients with advanced cancer to outpatient palliative care. Some of the main questions regarding system-oriented research in palliative care are summarised in panel 18.

A 2015 systematic review[52] highlighted 38 aspects of integration under five main domains: clinical structures, clinical processes, administration, education, and research. Although many ideas exist on how integration can take place, empirical data are lacking to show improved outcomes outside of a clinical trial. Few studies

A 2011 systematic review[16] that examined the quantity, design, and scope of palliative oncology publications, identified significant gaps in the literature. Of 1213 articles included over two 6-month periods, 365 (30%) were reviews or systematic reviews. More than half of the studies (n=438, 52%) focused on physical symptoms among patients with cancer, with few studies examining the interface between oncology and palliative care, and how palliative care can be better integrated with oncology to improve care. Patients with more than 6 months, 4–6 months, and less than 3 months to live each constituted approximately one-third of studies; however, patients with longer survival (>12 months) and very short survival (<1 month) were under-represented.[534] Only 6% of studies were randomised controlled trials, with low-quality reporting.[136] Thus, substantial opportunities to improve both the quantity and quality of palliative oncology studies remain.

have examined how routine symptom screening coupled with care pathways can be used to refer patients to palliative care.[348,535] Moreover, there is tremendous opportunity for joint research studies between oncology and palliative care teams to investigate the process of collaboration between the oncology and palliative care teams, such as multidisciplinary teams and embedded palliative care clinics.[536]

Resource limitations mean specialist palliative care for every patient is not possible. A proportion of patients with low levels of distress could be managed by their oncology team. In some countries, primary care also plays an important role as front-line provider. How much palliative care do oncology teams and primary care providers need to know[521] and deliver in their daily practice?[469] In a survey[174] of oncologists, greater knowledge and comfort with palliative care was associated with higher levels of self-reported palliative care delivery and specialist palliative care referral. Oncologists and palliative care teams can collaborate to examine how to better integrate palliative care competencies in oncology and primary care, and to document the patient care outcomes associated with this integration.

Another area of development in system-oriented research is the assessment of the level of integration among cancer centres. Such a metric would allow patients and clinicians to identify institutions that offer a high level of palliative care, researchers to examine progress, and administrators and policy makers to triage resources and develop quality improvement initiatives. A 2015 international Delphi study,[44] identified a high level of consensus for 13 indicators under four domains (clinical structure, process, outcomes, and education). Further studies are needed to validate this set of criteria.

Symptom assessment

There is considerable evidence that patients with advanced cancer develop multiple devastating physical and psychosocial problems,[537–539] and that these problems place substantial burden on their primary caregivers.[540,541] Frequent monitoring of these clinical problems will allow oncologists and palliative care specialists to identify patients who would benefit from various pharmacological and non-pharmacological interventions (see the background section of this Commission and the section on prognostication). More systematic prospective monitoring of symptoms might contribute to better prognostic models, which is warranted (see the section in this Commission on prognostication); however, the adoption of regular monitoring of patient-reported outcomes has been erratic. This inconsistency is partly because of the absence of standardisation or consensus on which domains require monitoring, the limited degree of validation of some instruments, the barriers to implementation of routine screening, and the need for more research to ascertain the real effect of screening on patient outcomes.[542,543]

Patients with chronic progressive diseases, including cancer, frequently receive care in multiple settings, including their home, acute care hospitals, palliative care units, inpatient hospices, and long-term care facilities.[35] The monitoring and screening of patient-reported and caregiver-reported outcomes needs to accompany the patient to those multiple settings. The Edmonton Regional Palliative Care Program did some pioneer research on adoption in multiple areas of care,[544–546] which was followed by several international initiatives.[547,548] More research is needed to define the best ways to provide valuable information to clinicians throughout the trajectory of patient care in multiple settings and clinical circumstances. Possible research opportunities in the area of screening and monitoring of patients with cancer and their caregivers are summarised in panel 19.

Palliative care and oncology teams need to work together to develop and validate novel assessment tools on various patient-reported outcomes, and apply these instruments in clinical and research settings to assess health outcomes. The patient-reported outcomes measurement information system has developed multiple assessments on the basis of computer adaptive testing, but these assessments require further testing.[549] In 2017, the International Consortium for Health Outcomes Measurement recommended a standard set of patient-centred outcomes for patients with colorectal and breast malignancies.[550,551] Assessment of personalised symptom goals might allow both oncologists and palliative care teams to determine the individual response to symptom interventions and further tailor treatments.[552]

Panel 19: **Research opportunities related to symptom assessments—research recommendations**

Symptoms and needs screening

- Which validated assessments should be used for which domains for screening in various clinical settings (eg, oncology, palliative care *vs* other specialties, or inpatient *vs* outpatient)?
- What instruments or assessments should be included in a standardised comprehensive palliative care assessment?
- How can patient function be assessed accurately?
- How can screening be best conducted for concepts such as patient understanding of illness, communication styles, spirituality, and caregiver needs?
- How can patient, health-care professional, and system barriers be overcome to facilitate routine screening in a busy oncology and palliative care practice?
- How can electronic data capture be used to collect and display patient-reported outcomes?
- What strategies can professional organisations adopt to support integration?
- How can investment in palliative care programmes be optimised to maximise the value of health-care expenditure?

Assessment of treatment response

- What is the minimum clinical important difference and responsiveness to change for various scales? How can personalised symptom goals be used to augment practice?
- What are the predictors of treatment response?

Panel 20: **Research opportunities related to symptom management—research recommendations**

Treatment toxicities
- How can adverse effects in clinical trials and daily practice be better assessed?
- What is the pathophysiology of adverse effects related to novel therapies?
- What are novel supportive care interventions for various treatment-related adverse events?

Cancer-related symptoms
- What is the pathophysiology, and what are the potential therapeutic targets?
- What combination of multimodal therapy has the greatest effect on symptom outcomes?
- What validated outcomes are required for regulatory approval for symptoms such as fatigue, cachexia, and dyspnoea?
- How to address chemical coping and opioid addiction in cancer patients while providing good pain control?

Panel 21: **Research opportunities related to psychosocial support, communication, and decision making—research recommendations**

Psychosocial, spiritual, and caregiver care
- What interventions are best for adjustment disorders?
- What are the strategies to screen for spiritual care needs in the medical setting?
- What are the best interventions to support caregivers along the disease trajectory?
- What are the strategies to support decision making?
- How can bereaved caregivers at risk of complicated grief be supported?

Communication and decision making
- How can survival in advanced diseases be accurately predicted, and used to support decision making?
- What are the strategies to communicate prognosis and help patients gain a better understanding of their illnesses without jeopardising the patient–clinician relationship?
- How can serious illness conversations be facilitated over the continuum of disease?
- How can decision-making aids and prompt sheets be standardised?
- How can physicians tailor the decision-making process to different decision making preferences among patients and families?

Symptom management

Multiple factors contribute to physical and psychosocial distress, including cancer location and burden, toxicities of cancer treatment, and comorbidities. As cancer treatment evolves, new treatments, such as targeted and immune therapies, have dramatically modified the risk-to-benefit ratio, adding another layer of complexity to cancer treatment decisions at the end of life.[181,553–555] Oncology teams are experts in the use of many of these new modalities, and palliative care teams are experts in symptom evaluation and management.

Many symptoms, such as fatigue, pain, anorexia, and dyspnoea, are highly prevalent throughout the disease trajectory.[556,557] In a systematic review and meta-analysis of 52 studies covering 40 years,[558] cancer pain was present in more than 50% of patients, and with one-third of patients reporting moderate or severe intensity, which was confirmed in a subsequent meta-analysis.[559] This high prevalence calls for more research and resources to improve the detection and treatment of pain by oncologists, palliative care specialists, pain medicine specialists, and other professions.

Although specialist palliative care has been found to improve symptom control compared with oncology care alone,[63] many symptoms have few effective therapies and remain undertreated even by a comprehensive palliative care team[552,560]—eg, anorexia-cachexia is reported in up to 60% of patients with advanced cancer. Management of cachexia should begin at the precachexia phase, when patients are seen predominantly by their oncologists. Here, multimodal multidisciplinary interventions targeting nutrition, physical activity, inflammation, appetite, and nutritional impact symptoms are essential.[561,562] Collaborative research between oncologists and palliative care teams to develop evidence-based palliative interventions can be fruitful (panel 20). By contrast, other issues, such as delirium and signs of impending death, mostly occur in the last days and weeks of life, and do not require a high degree of collaboration.[259,563,564]

Psychosocial issues and communication

Palliative care teams can support oncology teams in the delivery of psychosocial support and patient and family communication.[50,307,357] There is a great opportunity for research on the best methods for the delivery of effective psychosocial support, and on methods of communication with patients and their families. Randomised controlled trials can be done on physician body posture,[565,566] discussions regarding resuscitation,[567] and the effect of the content of the physician's message.[470] Better prognostication and prompt sheets might also enhance communication.[277,408,568,569] Important areas of psychosocial support, communication, and advance care planning in which palliative care teams can develop research initiatives together with oncology teams are summarised in panel 21.

Public health and implementation effect

The clinical and social contexts of death and dying in cancer are changing rapidly. Globally, WHO strongly supports advocacy efforts to make essential medicines available for palliative care. This public health policy work is grounded in the theory that, at a national level, palliative care programmes need to be context dependent and implementable. Place of death, place of care at the end of life, access to palliative care, circumstances of dying, and end-of-life decisions are strongly related to the health-care system, legal context, and type and models of palliative care available within a country. Therefore, more implementation research is needed regarding integration of palliative care and oncology.

Most evidence on integration of palliative care and oncology is based on clinical or health service evaluation studies done in only one or few hospitals.[3,5,47,50,58] In most countries, how well integration of early palliative care and oncology has been implemented throughout the

health-care system is, as yet, unknown. Palliative care is increasingly recommended in patients with cancer, but seldom offered to all in need. In an observational study[570] of 4466 deaths in four European countries, palliative care was shown to be delivered to 50% of patients in Belgium, 55% in Italy, 62% in the Netherlands, and 65% in Spain. Palliative care specialists attended to 29% of patients in the Netherlands, 39% in Italy, 45% in Spain, and 47% in Belgium. In this international study, patients with cancer were twice as likely to receive palliative care than patients with non-curable diseases. Furthermore, if palliative care is delivered, it is often initiated at the very end of life for most patients, when the patient is a few weeks before death. A nationwide study[571] in Belgium showed that the time of onset of palliative care is a median of 20 days before death for patients with cancer, as compared with 12 days in heart failure and 10 days in COPD.

Hence, this Commission shows that most patients do not receive palliative care early in their disease trajectories. Furthermore, the level of specialised care delivered to patients with advanced cancer in university hospitals often is quite different from the care in other settings. As the majority of the palliative care trials have been done in university hospitals, research findings are not necessarily applicable to other settings.[572]

New public health studies

New public health approaches present a new research perspective, using evidence from health promotion, health behaviour, and public awareness building.[573,574] Patients with cancer are cared for by oncologists or physicians for only a small amount of time—it is the spouses, families, and broader community that care for these people full time. Hence, the effect of family, volunteers, and the larger community is extremely important for patients with cancer; they support not only the patient's wellbeing, but also in the expression of their care preferences, participation in SDM, and eventually in the decisions at the end of life.

From this perspective, one should bear in mind that the general public, and thus public opinion, might not yet fully understand the potential of integration of early palliative care in an oncology treatment trajectory. The reality, in most countries, is that palliative care is still very much taboo or is associated with stigma because awareness and experiences of palliative care potential are limited to terminal care; hence, palliative care is associated with imminent death. To address this problem, we need research into the development of palliative care public awareness campaigns, human behaviour in health crisis situations, and empowerment of patients and families in making the right decisions both for their cancer treatment and for their wellbeing and quality of life.

To increase the amount of evidence concerning implementation of early palliative care in oncology and improvement of the involvement of patients, families, and the broader community in early palliative care, more public health-oriented research is needed alongside clinical and health services research. Important domains, possible research methods for monitoring the implementation of integration across a country, and possible research aims for public health studies relevant to integration of palliative care and oncology, are summarised in panel 22.

What are the opportunities for collaborative research regarding cancer treatments?

Palliative care teams are increasingly involved in the care of patients undergoing palliative therapies for advanced cancer, including systemic therapies, radiation, and surgical procedures. These teams have a crucial role in helping to maximise the quality of life of patients receiving cancer treatments, and also in facilitating the complex decision-making process surrounding treatments at the end of life (ie, the last months before death). The advent of novel therapies, such as immunotherapies, creates even more opportunities for collaborative research between the oncology and palliative care teams to optimise patient outcomes.

Exciting opportunities exist for joint research, through collaborative efforts by these two groups, which could lead to a better understanding of the pathophysiology of treatment-related adverse effects. The interaction between cancer burden, treatment toxicity, and comorbidities is complex and variable. As an example, a highly effective immunotherapy will reduce symptoms related to

Panel 22: **Research opportunities related to public and population health**

Recommendations of research methods

Monitoring implementation scope

- Administrative databases
- Health-care registries, eg, nationwide sentinel networks
- Nationwide post-mortem surveys
- Auditing of integrated care services

Recommendations of research aims

Evaluate the quality of integration of palliative care and oncology

- Development of palliative care quality indicators for the evaluation of the quality of the integrated services
- Cross-country and cross-setting (university hospital *vs* local hospital) validation of the indicators
- Implementation of the quality indicators
- Development of quality improvement interventions

Implement health-promoting early palliative care in cancer

- Assessment of the perceptions of palliative care potentials among cancer patients and their families, health-care professionals, and the general public
- Development of health promotion campaigns to empower cancer patients and their families to talk to their health professionals early in their illness trajectory about palliative care needs and care preferences
- Development of palliative care awareness campaigns to improve knowledge and attitudes towards early palliative care in cancer patients and the general public

the tumour mass and also improve the patient's and caregiver's psychological wellbeing, but will add symptoms related to fatigue and immune-related adverse effects, such as dermatitis, colitis, and hypophysitis.[575] Cancer, either through its direct effect on organs and tissues or its indirect effect on systemic mediators, can result in multiple symptoms, decreasing patients' functioning and quality of life. Cancer treatments might control tumour growth, but might also lead to significant toxicities. Comorbidities could further contribute to the overall symptom burden. Supportive care and palliative care aim to alleviate symptoms and improve quality of life by modulating the afferent signals and enhancing the coping mechanisms.

Palliative care specialists need not only to collaborate with surgeons, radiation oncologists, medical oncologists, and haematologists clinically, but also to conduct research studies to identify the best ways to optimise patients' functional status and nutritional status before, during, and after treatments. More research is also needed to determine the best strategies to prevent or treat various treatment-related adverse events.

Cancer treatments close to death are associated with reduced quality of end-of-life care.[576,577] Novel targeted therapies and immunotherapies are generally associated with fewer side-effects than conventional chemotherapy, and are increasingly offered to patients with reduced performance status.[555] A small proportion of these patients experience a remarkable treatment response, altering the natural history in a significant manner and adding to the prognostic uncertainty. Whereas oncologists can offer hope through new treatment opportunities, palliative care teams can nurture hope for better quality of life throughout the disease trajectory and help patients to balance the ever-shifting priorities. More collaborative research is needed to better understand patients' goals of care, illness understanding, and treatment preferences to develop better prognostication tools and decision aids to inform the complex decision-making process regarding treatment continuation and discontinuation as death approaches.[181,299]

***Panel 23*: Research—recommendations**

- Encourage research into new public health approaches for integration of oncology and palliative care by establishing international and national research programmes to support research on content, methods, and how to verify the effects
- Develop a minimum and maximum set of indicators for the follow-up of successes in the implementation of early integration of oncology and palliative care by initiating research programmes internationally and nationally
- Initiate collaborative research programmes in oncology and palliative care for symptom management (needs) and their application in secondary palliative care and in the discussion in multidisciplinary teams by initiating research programmes internationally and nationally
- Ensure top academic positions in palliative medicine or care (professors) are present at all academic cancer centres and medical schools by initiating professional awareness programmes and advocacy groups

Evolving models to support collaborative research

Compared with established medical disciplines, such as oncology, which focus on management of specific diseases, palliative care focuses on personhood care. Thus, palliative care specialists are uniquely positioned to do research by drawing on the similarities among different diseases to derive common principles of patient-centred care (eg, management of dyspnoea and serious illness conversations), while personalising management based on the unique differences among the different diseases (eg, cancer trajectory is more predictable).

Although there is no scarcity of academic oncologists, palliative care researchers are in short supply. Thus, educational programmes and funding opportunities are needed to train more palliative care clinicians in the principles of research and unique aspects of doing palliative care studies. Such investments will probably result in more opportunities for research collaborations, and will accelerate development of innovative interventions to improve patient care.

As new therapies become available to patients with cancer, opportunities will arise for oncology and palliative care teams to prepare proposals aimed at carefully measuring the effect of those therapies in the physical and psychosocial wellbeing of the patients, and the ideal management of the symptomatic complications secondary to those therapies. These proposals will provide access to sources of funding from industry, which traditionally have been largely unavailable to palliative care research teams. At a time when academic funding is becoming less available, these joint efforts will provide support for logistics and career development of academic palliative care physicians and oncologists.

Conclusion

Many questions related to the optimal delivery of palliative care in patients with cancer remain unanswered, with many challenges to high-quality research. With increased integration between oncology and palliative care, tremendous opportunities exist to identify novel research questions at the interface of disciplines, combine the resources to complete high quality research, generate new knowledge to advance symptom management and care delivery, and develop better models of integrated care to improve patient outcomes. Recommendations are presented in panel 23.

Summary and call for action

During the preparation of this Commission, the heterogeneity of the organisations, the content of the models, and the performance in clinical practices have become evident. The heterogeneity goes even further into the content of the education programmes, including the presence of palliative care in oncology training (if present at all), and the structure, content, and (absence of) formalisation of palliative medicine as a specialty in many countries. This heterogeneity together with the

absence of international agreements and standards of palliative care in oncology is probably the main barrier to successful integration. If one of the partners in a relationship is undefined or ambiguous, the probability to build a long lasting relationship will probably be low and very challenging.

Policy

Internationally, strong and clear resolutions and recommendations are given by WHO, OECD, professional organisations (ASCO, ESMO, EAPC), and international charters (EAPC, IAHPC, WPCA) on the place of palliative care as a part of cancer care programmes. The content and directions can be summarised by the statement given by the World Health Assembly: "Palliative care as an essential component of comprehensive care throughout the life course".[578] This states that palliative health services for non-communicable diseases should be covered under national universal health coverage plans. Several high-quality studies have shown that an integration of palliative care into oncology care improves outcomes like symptom management, patients' and family members' quality of life, and possibly survival for patients with short life expectancy. Systematic use of PROMs improves symptom control, reduce psychological distress, and can improve survival. The need for integration is further supported by the increase in incidence and prevalence of patients living with advanced cancer.

These clear and strong recommendations, which have arisen over the past couple of decades, are contrasted by the findings in this Commission: an absence of integration of oncology and palliative care. In most national cancer care plans, palliative care is not formulated as an integrated approach together with oncology. If it is present, it is often an add-on to the tumour-directed approaches. It seems to be a lack of willingness and capability to implement and prioritise palliative care in the cancer care plans, in care programmes, and in clinical care pathways.

The absence of true implementation might, in addition to the aforementioned factors, be related to the heterogeneity of the organisational models of palliative care, the absence of systematic education in palliative medicine in medical schools and during specialisation in oncology, and the lack of education about oncology during palliative medicine specialisation.

One might ask, has palliative care become even more underprioritised? Over the past decade, much attention has been given to the advances of new systemic tumour-directed therapies, and, at the same time, attention on patient-centred care might have dwindled.

To achieve improvements in complex systems like health care, several approaches are needed, and a combination of top-down and bottom-up actions are required (panel 24). In this Commission, we recommend that the strong political recommendations are followed up at national and regional levels. Together, politicians and the health-care bureaucrats need to develop plans and implementation strategies, and combine these plans with economic incentives and basic funding of the integration between oncology and palliative care. Palliative care might reduce costs, and improve the quality of life of patients and that of their family members.

Cultures

Cultures in health care play important roles by serving as invisible roadmaps for interpersonal interactions—eg, how a doctor communicates with a patient, or how physicians with different specialties interact. Cultures also act as barriers to the process of changing and improving practice. The oncology culture can be described as a tumour-directed culture, with its positive implication when the treatment goal is to cure and thereby achieve tumour control and, ideally, total eradication of the tumour. This culture has been, and is, essential to improve cure for many cancer diagnosis. However, from a patient's perspective, if cure is not achievable, a combined tumour-directed and patient-centred approach is needed, and strongly recommended in this Commission. In palliative care culture, the primary focus is to improve patients' quality of life. In this Commission, patient-centred care, including SDM with a primary focus on the patient (the host) is recommended. The palliative patient-centred culture therefore differs from the oncology culture: it has different players and has, until recently, been organised separately from mainstream health and oncology care in many countries. From the perspective of a patient in a non-curative situation, the palliative culture needs to be present and should not be

Panel 24: **Recommended national and international actions**

- True integration of oncology and palliative care must be recommended by national health-care authorities, followed up with resource allocation and priorities, and monitoring of successful implementation. International valid indicators of successful integration of oncology and palliative care are needed
- Analysis of the medical cultures and implementation of palliative care on the basis of the involvement of the leaders of the oncology and palliative care programmes are needed. The unofficial leaders at all levels also need to be mapped and involved in implementation plans
- International standards of oncology and palliative care are needed for: Integrated oncology and palliative care models to evaluate the effects of these models clinically; palliative care education in oncology and oncology education in palliative medicine; and definition of the necessary competence and the content of the education at the three different layers at a high level, preferably internationally, and not governed by tradition or local preferences
- Patient-centred care must be actively implemented into oncology care by means of systematic use of standardised care pathway where oncology and palliative care is fully integrated. Patient-reported outcome measures and shared decision making are methods that should systematically and actively be used in all parts of cancer care
- Investment in research is urgently needed to develop an evidence base on how to organise and perform palliative care in oncology practice. National earmarked grants for research programmes are needed, which are sufficiently funded for 3–5 years.

considered to be in competition, but rather synergistic or integrated with the tumour-directed culture.

One of several ways to understand why the patient-centred palliative care approach is not implemented into oncology clinics is the gap and antagonisms between the two cultures (panel 24). When different approaches from two cultures are to be blended in cancer care programmes, one needs to understand the differences and shared values, and plan the implementation according to a multicultural reality. The antagonisms held by the two maintain status-quo (ie, we *vs* them) is, in our view, a substantial barrier to integration.

Organisation and competence

The overall aim of the organisational model is that patients and their families have access to the care they need, when they need it, resulting in improved health-care outcomes. In the integrated oncology and palliative care model, early integration is a key concept. This concept illustrates that the content and competence of palliative care is much more than end-of-life care.

The multidisciplinary team approach can be used as a key component of the organisational model in hospitals to link oncology and palliative care services. However, the organisations need to do community and home care outreach. The models need to have a clear and robust organisation, but also be flexible according to the patients' needs. Several organisational models of palliative care have been developed and evaluated. This Commission recommends the models be divided into three levels: primary, secondary, and tertiary care. This Commission also recommends that the place and competence of oncology and palliative care need to be adjusted to the level of care and the patients' needs. At the primary health-care level, general practitioners need to have the necessary competence in palliative care. Their role is central in home care.

One limitation of the organisational models identified in the literature and discussed in this Commission is their heterogeneity, which hinders the generalisation of findings. This Commission has identified a need to develop international standards for the structure and content of the organisational models, and to further evaluate the effects in public health-care research.

For the successful integration of oncology and palliative care, a multidisciplinary approach is needed (panel 24). The health-care providers need skills in patient-centred care. Wide variations in education have been identified for oncologists and palliative medicine specialists, and variations also exist for education of the other participants in the multidisciplinary teams. The general lack of competence in palliative care is also a barrier to successful implementation of the integrated models.

Patient-centred care

The concept of total pain, which is central in palliative care, infers a broad understanding of patients' needs during a disease trajectory. Many patients with cancer undergo life-prolonging treatment for years, or are cancer survivors with manifest or latent late effects of treatments. Therefore, the chronic disease model is highly relevant in oncology, but is seldom referred to or used.

Patients and their families expect, and demand, to be actively involved in the care planning at all stages of the disease trajectory. A central part of the involvement and engagement of patients is a systematic collection of the patients' voice. Expectations exists about information and communication to patients about treatment and care plans, which often are not fulfilled when it comes to patients with advanced disease and a limited life expectancy. Often, they are not aware of their disease status, and the expected effects of tumour-directed treatment.

The fragmented nature of the cancer care system calls for a method to implement the planning and coordination, and to allocate resources according to patients' needs. An SCP is a method to plan and implement complex health services, and to ensure that the right people are at the right place at the right time. This Commission proposes the use of SCP as a model to develop a seamless patient flow in a customised organisational model.

Symptom assessment by systematic use of validated PROMs is pivotal for patient-centred care throughout the whole cancer disease trajectory. Symptom assessment is a key method to engage patients in the decision-making processes in which PROMs are key information to customise the SCPs. PROMs were traditionally collected via paper-based questionnaires. This Commission recommends development and use of electronic tools for collection of e-PROMs that can be integrated into the electronic patient record systems.

SDM is another central component of patient-centred care. It is highly relevant in all phases of cancer treatment, but is even more central for patients with advanced non-curable disease. SDM is an active and continuous process, combining the tumour-directed and patient-centred approaches in the care planning. This Commission recommends SDM is included as a mandatory part of oncology guidelines, and is visualised in the content of the SCPs (panel 24).

Research

Early integration of oncology and palliative care gives new arenas and opportunities for collaboration to address new research questions. Some key questions to answer are related to health-service issues and others to patient-related issues, such as assessment and treatment of physical symptoms, psychological distress, communication, and decision-making processes and performances.

New tumour-directed treatments, such as targeted and immune therapy, have added another layer to the complexity of the end of life. These treatments give new opportunities for collaborative research in addressing the

interactions between tumour burden, treatment toxicity, and comorbidities. At the health-service arena, several questions remain unanswered. How can integration of oncology and palliative care be optimised? What are the optimal organisational models at the primary, secondary, and tertiary levels of care for integrated oncology and palliative care? How can the human resources be used optimally in the SCPs?

Research competence and funding are basic (panel 24). Few resources are allocated to palliative and end-of-life care research. Data from several countries indicate that 0·3–1% of resources allocated to cancer research go to cancer palliative care research. Insufficient research funding also minimises the opportunities for training physicians in palliative care research, and thereby qualify clinicians to be researchers and to apply for academic positions.

Contributors

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PROGETTO

"CURE PALLIATIVE IN C.S.A"

Sviluppo delle Cure palliative nei C.S.A.:

(Centro Servizi per Anziani)

- **gestione della fase di fine vita in CSA.**
- **Lotta al dolore inutile.**

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INTRODUZIONE

Nel mondo occidentale la percentuale di anziani con oltre 65 anni che vivono in CSA varia dal 2 % al 8%, tale valore sale al 20% se si considerano gli ultra ottantacinquenni e di questi la maggior parte si trova ad affrontare un periodo più o meno lungo di fine vita prima della morte. A titolo di esempio, nella sola Olanda, ogni anno il 34% dei residenti nelle "Nursing Home" entra in fase di fine vita.

In linea generale i pazienti che decedono nelle residenze per anziani possono essere affetti da patologie oncologiche e da patologie cronico-degenerative (tra cui la demenza di diversa origine) che portano a una perdita delle funzioni motorie e cognitive (compresa la capacità di comunicare i propri sintomi e le proprie sofferenze) in uno spazio di tempo variabile, a volte anche molto ampio, con episodi di aggravamento che si alternano a periodi di relativa stabilità.

La necessità di fornire anche agli ospiti dei CSA un adeguato riconoscimento e trattamento dei sintomi rappresenta quindi una crescente necessità, sia che si tratti di persone in grado di comunicare i propri bisogni, sia che si tratti di persone affette da demenza di vario grado con una capacità di comunicazione più o meno compromessa.

Oltre a ciò è stato stimato che la prevalenza del dolore negli anziani istituzionalizzati varia dal 45% all'85% e, si ritiene che, almeno in parte, tale variabilità sia dovuta al mancato riconoscimento e/o alla mancata misurazione del sintomo dolore.

Le cause del dolore nel paziente anziano sono molteplici, escluse le cause oncologiche, il dolore in questi pazienti può avere origine da malattie degenerative, ischemiche, respiratorie ecc. ma spesso l'anziano presenta anche Dolore Cronico di entità moderata/severa multifocale oltreché multifattoriale.

Bisogna inoltre considerare che nel paziente anziano, ospite di CSA, il dolore non va identificato solo come sintomo fisico, bensì come elemento bio-psico-sociale coinvolgente

cioè la più ampia sfera della persona, identificando quindi la **"sofferenza"** quale sintomo dove il dolore può essere presente, ma non ne rappresenta l'unico elemento.

Costituiscono parte integrante della sofferenza anche lo stato d'animo indotto dalla istituzionalizzazione, il distress respiratorio da molteplici cause, l'inabilità, la depressione, l'insonnia ecc.

PREMESSA

La Legge n. 38 del 15 marzo 2010 **"Disposizioni per garantire l'accesso alle cure palliative e alla terapia del dolore"** tutela il diritto di tutti i cittadini ad accedere alle cure palliative e alla terapia del dolore, per ogni età, per ogni patologia, per ogni luogo di cura a tal fine impegna le strutture sanitarie ad assicurare un programma di cura individuale per il malato e per la sua famiglia, senza alcuna discriminazione, al fine di tutelare la dignità e l'autonomia del malato, promuovendo la qualità della vita fino al suo termine.

Secondo questa legge, le strutture sanitarie devono assicurare un programma di cura individuale per il malato e la sua famiglia, nel rispetto dei seguenti principi:

- Tutela della dignità e dell'autonomia
- Tutela e promozione della qualità della vita fino al suo termine
- Sostegno sanitario e socio assistenziale alla persona malata e alla famiglia.

Lo strumento operativo che ha il compito di garantire, organizzare ed erogare le Cure Palliative è la **Rete Locale di Cure Palliative** che comprende strutture Ambulatoriali, Residenziali Ospedaliere e Residenziali del Territorio e fra queste le Residenze Sanitarie Assistenziali.

In questi termini le Strutture Socio Sanitarie ed Assistenziali devono attivarsi per far si che anche i propri residenti ricevano cure palliative appropriate nella fase di fine vita e del morire.

L.E.A: (livelli essenziali di assistenza)

Decreto del Presidente del Consiglio dei Ministri, 12 gennaio 2017.

Art. 23

1. Il Servizio sanitario nazionale garantisce le cure domiciliari palliative di cui alla legge 15 marzo 2010, n. 38, nell'ambito della Rete di cure palliative a favore di persone affette da patologie ad andamento cronico ed evolutivo per le quali non esistono terapie o, se esistono, sono inadeguate o inefficaci ai fini della stabilizzazione della malattia o di un prolungamento significativo della vita. **Le cure sono erogate dalle Unità di Cure Palliative** (UCP) sulla base di protocolli formalizzati nell'ambito della Rete e sono costituite da prestazioni professionali di tipo medico, infermieristico, riabilitativo e psicologico, accertamenti diagnostici, fornitura dei farmaci di cui all'art. 9 e dei dispositivi medici di cui agli articoli 11 e 17, nonché dei preparati per nutrizione artificiale, da aiuto infermieristico, assistenza tutelare professionale e sostegno spirituale. Le cure palliative domiciliari si articolano nei seguenti livelli:

a) **livello base: costituito da interventi coordinati dal medico di medicina generale (MMG) o dal pediatra di libera scelta (PLS)**, secondo quanto previsto dall'art. 2, comma 1, lettera f) della legge 15 marzo 2010, n. 38, che garantiscono un approccio palliativo attraverso l'ottimale controllo dei sintomi e una adeguata comunicazione con il malato e la famiglia; sono erogate da medici e infermieri con buona conoscenza di base delle cure palliative e si articolano in interventi programmati caratterizzati da un CIA minore di 0,50 in funzione del progetto di assistenza individuale;

b) livello specialistico: costituito da interventi da parte di **équipe multiprofessionali** e multidisciplinari dedicate, rivolti a malati con bisogni complessi per i quali gli interventi di base sono inadeguati; richiedono un elevato livello di competenza e modalità di lavoro interdisciplinare. In relazione al livello di complessità, legato anche all'instabilità clinica e ai sintomi di difficile controllo, sono garantiti la continuità assistenziale, interventi programmati caratterizzati da un CIA maggiore di 0,50 definiti dal progetto di assistenza individuale nonché pronta disponibilità medica e infermieristica sulle 24 ore.

2. Le cure domiciliari palliative richiedono **la valutazione multidimensionale**, la presa in carico del paziente e dei familiari e la definizione di un «Progetto di assistenza individuale» (PAI). Le cure domiciliari palliative sono integrate da interventi sociali in relazione agli esiti della valutazione multidimensionale.

Decreto del Presidente del Consiglio dei Ministri, 12 gennaio 2017

Art. 31

1. Il Servizio sanitario nazionale, nell'ambito della rete locale di cure palliative, garantisce alle persone nella fase terminale della vita affette da malattie progressive e in fase avanzata, a rapida evoluzione e a prognosi infausta, il complesso integrato delle prestazioni mediante l'impiego di metodi e strumenti basati sulle più avanzate evidenze scientifiche, mediche specialistiche, infermieristiche, riabilitative, psicologiche, gli accertamenti diagnostici, l'assistenza farmaceutica e la fornitura di preparati per nutrizione artificiale, le prestazioni sociali, tutelari e alberghiere, nonché di sostegno spirituale. Le prestazioni sono erogate da équipe multidisciplinari e multiprofessionali nei Centri specialistici di cure palliative-Hospice che, anche quando operanti all'interno di una struttura ospedaliera, si collocano nell'ambito dell'assistenza sociosanitaria territoriale.

2. I trattamenti di cui al comma 1 sono a totale carico del Servizio sanitario nazionale.

GLI ATTORI DEL PROGETTO

ULSS 1 Dolomiti: l'Azienda Sanitaria ULSS 1 Dolomiti, richiamata la delibera n° 1213 del 23 ottobre 2017, attraverso la quale intende aumentare la capacità di erogare cure palliative a tutti i cittadini aventi bisogno, pervenendo all'integrazione fra Ospedale e Territorio e potenziando le cure domiciliari, accoglie e fa proprio l'intendimento di Mano Amica.

Il Direttore Generale promulga la delibera 115/2018: "*Sviluppo delle cure palliative nelle strutture residenziali per anziani. Progetto Sperimentale.*"

L' ULSS 1 Dolomiti attua la delibera 115/2018 attraverso il Distretto e in particolare attraverso il medico di **Medicina Generale.**

Mano Amica: l'Associazione Mano Amica si è data nel proprio statuto, fra i vari, il compito di sviluppare la conoscenza, la diffusione e lo sviluppo delle Cure Palliative.

L'Associazione Mano Amica con atto proprio in data 27 novembre 2017, prot. 463/17, propone all'Azienda Sanitaria ULSS 1 Dolomiti l'avvio di un progetto volto a sviluppare le cure palliative nelle Residenze Sanitarie per Anziani.

Agisce per conto di Mano Amica, nella veste di tutor esperto, nonché come fiduciario della stessa, il dr. Giampietro Luisetto, master di 2° livello in terapia del Dolore e Cure Palliative.

Azienda Feltrina per i Servizi alla Persona: l'Azienda Feltrina per i Servizi alla Persona**:** ispira ed orienta la propria attività socio sanitaria perseguendo le seguenti intenzioni:

a) il rispetto della dignità della persona;

b) la flessibilità e l'adattabilità alle diverse condizioni dei bisogni di ogni singolo utente e ai cambiamenti che si possono manifestare durante la presa in carico;

c) l' elevata reattività, intesa come tempestività di risposte alle dinamiche delle condizioni degli utenti;

d) la professionalità e competenza dei collaboratori, sul piano del contenuto degli interventi e, in particolare, delle relazioni con gli utenti, per garantire una condizione di agio e di sicurezza, fondamentale per il loro benessere;

e) la specializzazione professionale per garantire nel tempo un miglioramento continuo della qualità dei servizi e unitarietà del l'intervento.

Ed è proprio a partire da queste intenzioni che l'Azienda aderisce favorevolmente alla proposta dell'Associazione Mano Amica per l'avvio di un progetto, in collaborazione all' ULSS 1 Dolomiti di Feltre, avente la finalità di sviluppare le cure palliative all'interno delle RSA, allo scopo di alleviare il dolore e fornire sollievo ai gravi sintomi della malattia, soprattutto nella delicata fase del fine vita, senza perdere di vista l'aspetto psicologico e spirituale nel processo del prendersi cura.

l'A.p.s.p. "Valle del Vanoi": l'A.p.s.p. "Valle del Vanoi", Azienda pubblica di servizi alla persona operante nel territorio Trentino, nella limitrofa valle del Vanoi ha come mission la cura e l'assistenza dell'anziano, nel rispetto della sua dignità ed integrità come persona fragile. L'A.p.s.p. Valle del Vanoi eroga cioè servizi sanitari, assistenziali ed animativi nella continua ricerca dello status ottimale propri residenti; secondo le modalità previste dai piani nazionali e provinciali e nella consapevolezza che nulla potrà colmare il vuoto della mancanza del proprio domicilio, ambisce a far sentire i propri anziani bene come a casa loro. I principi ispiratori sono quindi affini a quelli dell'Azienda Feltrina, e il progetto proposto dall'Associazione Mano Amica rappresenta un'opportunità di trasferire il sostegno nella fase di fine vita e nel morire già ben strutturato a livello territoriale e domiciliare anche in C.S.A.

I C.S.A della Provincia di Trento sono già tenuti alla segnalazione obbligatoria al servizio di Cure Palliative dei loro residenti affetti da una patologia oncologica, mentre sono invitate a farlo, in un'ottica di eccellenza, per gli ospiti non oncologici in fase terminale.

ANALISI DEL CONTESTO

La **Casa di Riposo Brandalise** con sede a Feltre, che accoglie in regime di residenzialità 145 ospiti. Di cui attualmente:

- ✓ 105 non autosufficienti di cui 8 di 2° livello e 97 di 1° livello
- ✓ 10 persone con demenza di Alzheimer con importanti disturbi comportamentali (SAPA)
- ✓ 1 ospite in stato vegetativo permanente
- ✓ 26 persone autosufficienti o parzialmente auto.
- ✓ 3 non autosufficienti in regime privato

L'A.P.S.P " Valle del Vanoi" con sede in Canal San Bovo, provincia di Trento, che accoglie in regime di residenzialità 68 ospiti.

Di cui attualmente:

- ✓ 61 non autosufficienti di cui 55 convenzionati con l'Azienda sanitari e 6 in regime di privato dei quali 15 persone con demenza di Alzheimer e con importanti disturbi comportamentali;
- ✓ 7 autosufficienti.

I residenti di entrambe le strutture sono per lo più di Grandi Anziani affetti da patologie cronico degenerative che determinano condizioni di non autosufficienza, fragilità e sofferenza psico-fisica e anche gli utenti autosufficienti sono comunque in situazioni socio sanitarie per lo più suscettibili al peggioramento e alla perdita di autonomia.

DESTINATARI DEL PROGETTO

Il progetto in questione è destinato ad anziani con un'aspettativa di vita presumibilmente non superiore all'anno.

Il progetto coinvolgerà :

61 ospiti della C.S. Brandalise di cui:

- ✓ 29 ospiti, di cui 7 con profilo di 2° livello dal nucleo "il Giardino"
- ✓ 32 persone per lo più affette da demenza di Alzheimer con problemi comportamentali dal nucleo " Il Glicine"

30 ospiti non autosufficienti dell'A.p.s.p. Valle del Vanoi

OBIETTIVI DEL PROGETTO

OBIETTIVO GENERALE

Il progetto si pone l'obiettivo di garantire l'accesso precoce ed appropriato alle cure palliative e alla terapia del dolore anche agli ospiti dei C.S.A. Per questo è fondamentale individuare precocemente le persone per le quali, a causa della/e patologie di cui sono affette, non sembra più appropriato un percorso di cura volto alla guarigione e basato su interventi saltuari in acuzie bensì un percorso attivo e continuo, trasversale alle varie strutture sanitarie aziendali, ospedaliere e territoriali, che privilegi la qualità di vita residua, così da poter condividere con loro e la loro famiglia un programma di interventi

mirati a migliorare la qualità di vita nella fase del morire attraverso l'eliminazione del dolore fisico, e lo sviluppo di tecniche volte al benessere psico-sociale e spirituale dell'utente e della sua famiglia.

Il progetto si basa su alcuni punti fondamentali:

1) **Studio epidemiologico** sugli ospiti delle CSA deceduti nel 2017.

2) **Individuazione degli ospiti che si pensa possano beneficiare di cure palliative** e loro segnalazione al servizio di cure palliative.

3) **Formazione** verso tutti gli operatori dei CSA.

4) **Coinvolgimento dei medici di medicina generale** che hanno in carico i pazienti, in vista di una loro adesione al progetto e una loro maggior competenza ed autonomia nella gestione delle cure palliative di base.

5) **Coinvolgimento del nucleo di Cure Palliative** e degli specialisti ospedalieri (geriatri, pneumologi, neurologi, nefrologi, cardiologi, ….) con l'obiettivo di evitare trasferimenti di pazienti presso i reparti ospedalieri, quando lo stesso risultato terapeutico si renda possibile in modo appropriato e sicuro nel luogo di residenza del paziente. La valutazione specialistica potrà essere effettuata presso il C.S.A., quando non richieda una particolare strumentazione diagnostica.

OBIETTIVI SPECIFICI

Gli obiettivi specifici del progetto risultano essere i seguenti:

1. **Sensibilizzazione, coinvolgimento e partecipazione dei MMG di struttura.**

2. **Individuare tempestivamente le persone in fase di terminalità:**
   Introdurre strumenti di valutazione ad uso di tutto il personale utili a definire quali pazienti siano da avviare ad un percorso di cure palliative di base e specialistiche. (CFR. LEA 2017)

3. **Segnalazione alla Centrale Operativa Territoriale (C.O.T):**
   Segnalare alla Centrale Operativa Territoriale e all'Unità Operativa di Cure palliative tutti i pazienti individuati al fine di istruire l' Unità di Valutazione Multidimensionale Ospedaliera (UVMO) e/o l' Unità di Valutazione Multidimensionale Distrettuale (UVMD).

4. **Effettuare una UVMD per ogni utente individuato:**

l'UVMD/O costituisce la porta d'accesso alle prestazioni di cure palliative, si tratta di una valutazione multidimensionale del paziente. Essa è effettuata dal MMG. dal medico Palliativista, dallo **specialista ospedaliero** per la patologia principale (generalmente il paziente ha già una storia clinica precedente all'UVMD), dall'infermiere, dalla psicologa, dal terapista della riabilitazione, dall'assistente sociale.
Lo scopo dell'UVMD è di formulare un Piano Individuale Assistenziale, condiviso negli scopi, che orienti il percorso di cura congiuntamente attuato, rivalutabile nel tempo e che accompagni il paziente fino all'exitus.

5. **Garantire l'accesso dell' èquipe di cure palliative ai C.S.A.:**
   Al passaggio dalle Cure Palliative di Base (coordinate dal MMG.) alle Cure Palliative Specialistiche si rende necessario l'accesso del personale specialistico dell' U.O.C.P. ai C.S.A, quando richiesto dal medico della struttura e nel rispetto del P.A.I redatto in sede di UVMD.
   L' U.O. C.P. presiede e coordina l'attuazione del P.A.I. nella fase specialistica.

6. **Garantire l'accesso degli specialisti ospedalieri alle C.S.A.:**
   a seguito di quanto individuato nel P.A.I lo specialista ospedaliero accede al C.S.A. per le rivalutazioni programmate e/o su richiesta del MMG di C.S.A. nelle situazioni emergenti non previste all'atto della stesura del piano assistenziale.

7. **Migliorare la qualità di vita e la qualità del morire negli ospiti residenti in CSA:**
   - ✓ implementare l'uso di scale di valutazione dei sintomi e in particolare del sintomo dolore,
   - ✓ implementare, migliorare ed applicare tecniche per il controllo dei sintomi e per la gestione della fase terminale della vita,
   - ✓ migliorare l'uso dei farmaci in particolare i farmaci antalgici,
   - ✓ ridurre il ricorso agli accessi al pronto soccorso,
   - ✓ ridurre il ricorso al ricovero ospedaliero, favorendo la permanenza dell'ospite al proprio domicilio, ovvero in CSA,
   - ✓ ridurre il n° di decessi in ospedale.

8. **Attuare un programma di formazione per tutto il personale:**
   - L'intervento formativo ha la finalità di aiutare il personale sanitario dei CSA a riflettere sulla necessità di applicare criteri di appropriatezza alla cura dei malati con demenza avanzata e non (proporzionalità degli interventi).
   - Rilevare, individuare le cause e trattare i principali sintomi (dolore ,dispnea , delirium, ecc).

- Riflettere sulle problematiche concernenti scelte cliniche controverse (alimentazione e idratazione artificiali, sedazione terminale), ruolo e comunicazione con la famiglia, in particolare nell'imminenza del decesso**.**

9. **Condividere con l'ospite e la sua famiglia il programma di interventi mirati a migliorare la qualità di vita nella fase del morire:**

   - ✓ Dialogo con gli utenti competenti secondo il disposto della legge 22 dicembre 2017, n° 219: "Norme in materia di consenso informato e di disposizioni anticipate di trattamento"
   - ✓ Sensibilizzare i familiari rispetto alla cultura di "qualità della vita del morire" e sulle modalità d'intervento adottate dal CSA;

10. **Effettuare uno studio epidemiologico sugli ospiti dei CSA deceduti nel 2017 e raccolta dati sui pazienti individuati per accedere alle cure palliative nel 2018 e mettere a confronto i dati raccolti.**

MOTIVAZIONI SCIENTIFICHE

Numerosi dati di letteratura confermano che l'attuazione delle azioni descritte nel piano in oggetto permettono di avere:

1 -Miglioramento della qualità di vita e della qualità del morire (dati misurabili attraverso indicatori di salute/benessere oggettivabili – come le scale psicometriche accreditate) tra gli utenti dei CSA;

2 -riduzione dei punteggi di dolore schedati e monitorabili nel tempo dall'ingresso alla dimissione;

3 -miglioramento del tono dell'umore;

4 -miglioramento della qualità del sonno e conseguente migliore gestione dei presidi farmacologici correlati (es. riduzione del ricorso a farmaci sedativi, in relazione alla correzione del fenomeno dolore spesso co-responsabile di insonnia ed alterazioni umorali correlati ai disturbi del sonno);

5 -miglioramento delle condizioni psicofisiche eanche negli utenti gravemente compromessi;

6 -riduzione delle complicanze da allettamento e compromissione generale.

7 -migliore approccio terapeutico nel governo del fenomeno dolore nei soggetti affetti da demenza e sindromi correlate, considerato quanto l'abolizione dello stesso porti talvolta a sensibili miglioramenti di disturbi di carattere comportamentale;

8 -progressiva riduzione di fenomeni correlati a refrattarietà al dolore e ad effetti collaterali connessi alle scelte terapeutiche adottate;

9 -riduzione dei tempi di assestamento in relazione alla strategia farmacologica e non farmacologica designata, dal momento della diagnosi e/o del riscontro di dolore al momento di completo controllo dello stesso;

10 -sensibile miglioramento nell'assistenza globale alla persona in fase di fine vita in tutti i suoi aspetti, secondo un paradigma decisamente olistico sia nell'approccio al morire sia nella sfera più prettamente personale, psicologica ed emozionale in questa fase così intima ma ultima del vivere;

11 -riduzione degli accessi impropri ai servizi di Pronto Soccorso;

12 -riduzione dei ricoveri impropri presso il presidio ospedaliero in situazioni gestibili in CSA.

13 -diffusione della cultura di "qualità della vita nel morire" (personale, familiari, comunità);

14 -riduzione del ricorso a mezzi di contenzione fisica e farmacologica;

15 -progressivo miglioramento dei profili motivazionali del personale che opera a contatto diretto con l'utenza delle CSA, con parallela riduzione dei fenomeni di burn-out da parte degli stessi. Un team costantemente formato sul tema e parte attiva ai progetti in oggetto non può che dare frutto alle conoscenze acquisite, nonché migliorare la propria performance in termini qualitativi in relazione alle competenze professionali tipiche del proprio ruolo.

FASI DEL PROGETTO

Fase	Attività
Plan	Progettazione e budget del progetto
Do	Dati decessi 2017 e indagine epidemiologica
	Quadro generale dell'utenza coinvolta
	Informazione/formazione del personale
Act	Identificazione degli ospiti in fase di terminalità
	Presa in carico e informazione al familiare
	Formulazione del PAI e sua implementazione
	Chiusura del PAI a decesso avvenuto e raccolta dati
Check	Verifica indicatori di processo e di esito formulati: dati 2017 e dati 2018 Somministrazione questionario di gradimento operatori e familiari. Analisi dati e formulazione risultati Validazione del progetto da parte di "esperti esterni indipendenti" Valutazione intermedia e finale dei risultati da parte di "esperti esterni indipendenti"

ARTICOLAZIONE OPERATIVA DEL PROGETTO:

	Fasi	**Strumenti**	**Tempi previsti indicativi**	**Out put**	**Risultato**
Approvazione definitiva del progetto	Presentazione progetto all'associazione Mano Amica	Assemblea	25 aprile 2018	Documento	Comunicazione Associazione e approvazione progetto
	Incontro/i responsabili Enti interessati per pianificazione programma	Riunione	16 maggio 2018	Documento	Verbale
	Definizione degli obiettivi intermedi e degli indicatori di processo e di esito	Lavoro e condivisione	Entro maggio 2018	Identificazione obiettivi specifici ed indicatori	Verbale

	Fasi	Strumenti	Tempi previsti indicativi	Out put	Risultato
	Validazione del progetto		Entro maggio 2018		Relazione da parte di esperti esterni indipendenti: dr.Franco Toscani, dr.Renzo Pegoraro
	Presentazione e approvazione definitiva da parte del CDA Azienda Feltrina Servizi alla Persona, A.p.s.p. Valle del Vanoi , AULSS 1 Dolomiti, APPS Trento.	Riunione	Entro maggio 2018	Scheda progettuale	Delibera di approvazione
Responsabilità: responsabile della costruzione del progetto: dott. Alessio Gioffredi. Gruppo di lavoro: • rappr/te Mano Amica dr. Giampietro Luisetto. • Rappr/ti RSA" Brandalise": Zabot Federica,D' Agostini Loredana, Pellencin Lara. • Rappr/ti A.p.s.p. Valle del Vanoi: Zortea Cinzia, Iagher Elena. • Azienda AULSS1: Direttore di Distretto, Direttore d'Ospedale, Responsabile U.O.C.P. Validatori esterni: dr. Franco Toscani Direttore Scientifico Fondazione "Lino Maestroni" Istituto di Ricerca Scientifica Cremona dr. Renzo Pegoraro : direttore scientifico della Fondazione "Lanza" di Padova e Cancelliere presso la Pontificia Academia Pro Vita. Città del Vaticano Approvazione del progetto: Direzione Generale AULSS1, Mano Amica, APPS Trento, Direzioni C.S.A..					
Organizzazione operativa	Programmazione Formazione del personale	Individuazione argomenti e docenti	Entro giugno 2018	Piano della formazione specifico	Approvazione piano formazione
	Raccolta dati (individuati come da indicatori) ospiti anno 2017	Raccolta documentale	Entro luglio 2018	Banca dati per singolo Ente	Report dati 2017
	Raccolta dati (individuati come da indicatori) ospiti anno 2018	Lavoro del singolo	Contestuale anno 2018	Banca dati per singolo Ente	Report dati pazienti a fine 2018
		1° Riunione di condivisione	Entro luglio 2018		

	Fasi	Strumenti	Tempi previsti indicativi	Out put	Risultato
	Attivazione Formazione del personale	Organizzazione e logistica	Dal mese di settembre 2018	Piano della formazione specifico	
	Definizione delle modalità di accesso e delle modalità operative degli specialisti ospedalieri e del palliativista nei C.S.A.	Riunione	Entro luglio 2018	Direttive Aziendali Ospedaliere e Distrettuali	
Organizzazione operativa	Definizione di procedure per il trattamento dei sintomi condivise con i C.S.A. coinvolti	Riunione Responsabili Enti coinvolti per validazione delle procedure	Anni: 2018 2019 2020	Procedure formalizzate	Acquisizione di una metodologia di standardizzazione dei processi
	Implementazione trattamenti definiti nelle procedure	Procedure validate	Anni: 2018 2019 2020	Sollievo dai sintomi	
Responsabilità: MMG di C.S.A., dott. Giampietro Luisetto, Direttore di Distretto, Direttore Ospedale, Responsabile UOCP, **specialisti ospedalieri secondo la patologia,** rappr/ti CSA. Brandalise": Zabot Federica,D' Agostini Loredana, Pellencin Lara, rappr/t i A.p.s.p. Valle del Vanoi: Zortea Cinzia, Iagher Elena.					
Follow-up	Raccolta opinione lavoratori e familiari	Questionario	Marzo 2019	Report questionari	
	Analisi dati 2017 - 2018	Verifica indicatori	Febbraio 2019	Documento di analisi	
	Verifica raggiungimento obiettivi	Risultati ottenuti	Marzo 2019	Documento di risultato	
Responsabilità: rappr/ti RSA, dr. Giampietro Luisetto, valutatori esterni: dr. Franco Toscani, dr. Renzo Pegoraro.					
Valutazione critica risultati	riunione	Marzo 2019	Mantenimento o correzione del progetto	Validazione progetto	

	Fasi	Strumenti	Tempi previsti indicativi	Out put	Risultato
Presentazione dati	Forum	Dicembre 2019	Documento finale		
Responsabilità: rete locale di cure palliative: dr. Roberta Perin.					

La fase organizzativa/operativa e il follow-up si ripetono ogni anno.

PERCORSO DI FORMAZIONE

Fa parte integrante del progetto la formazione del personale sanitario e assistenziale, considerata fondamentale per l'applicazione pratica dei presupposti e delle finalità teoriche del progetto.

Il percorso di formazione si sviluppa nell'arco di tre anni.

✓ DESTINATARI

Personale sanitario e socio assistenziale dei C.S.A. aderenti

✓ FINALITA' DELLA FORMAZIONE

L'intervento formativo che si vuole porre in essere nel percorso progettuale, ha una duplice finalità:

1. **Sensibilizzazione del personale**: alla fine del percorso formativo il personale sanitario e assistenziale dei CSA sarà in grado di riflettere sulla necessità di applicare criteri di appropriatezza alla cura dei malati con demenza avanzata e non (proporzionalità degli interventi).

2. **Accrescimento di competenze**: alla fine del percorso formativo il personale sanitario e assistenziale sarà in grado di:
   - ✓ rilevare e trattare in maniera appropriata i principali "sintomi" manifestati nella fase di fine vita e del morire (dolore ,dispnea , delirium ecc)
   - ✓ riflettere e lavorare in equipe sulle problematiche concernenti scelte cliniche controverse (alimentazione e idratazione artificiali, sedazione terminale)
   - ✓ avere un ruolo di comunicazione e sostegno alla persona e alla famiglia, in particolare nella fase del morire.

✓ MODALITA' DI FORMAZIONE

Lezioni frontali teorico/pratiche programmate secondo incontri periodici sugli argomenti bersaglio. La docenza verrà assegnata, per quanto possibile, ad eventuali esperti già presenti nei C.S.A, nella realtà dell'ULSS 1 Dolomiti e presso l'Azienda Sanitaria di Trento.

✓ CONTENUTI – ARGOMENTI BERSAGLIO

	TEMATICA	**ore**	**DOCENZA**
1	• Presentazione del progetto. • L'impresa e l'équipe. • L'appropriatezza degli interventi. Tra cura e accanimento".	2	Relatore qualificato (esperto in appropriatezza delle cure)
2	Riconoscere il paziente da inserire in un programma di cure palliative: • La rete locale di cure palliative: composizione, compiti, responsabilità. • il paziente oncologico, • il paziente cardiopatico, • il paziente bronco-pneumopatico, • il paziente nefropatico, • il paziente neurologico, • il paziente con demenza,	7	Specialista di patologia Medico palliativista
3	La morte e il lutto: significati, riti e simboli nella nostra società multiculturale. L' assistenza spirituale	2	Sociologo/psicologo
4	Le fasi del morire (Kubler Ross ed altri modelli) i meccanismi di difesa; il morente e le relazioni significative; la paura della morte.	2	Psicologo
5	Riconoscimento e trattamento dei sintomi del malato in fase terminale: competenze mediche infermieristiche e degli OSS. Interventi farmacologici e non farmacologici.	2	Medico Infermiere O.S.S.
6	Il nurturing touch		Psicologo

			Fisioterapista
7	Cenni di bioetica nella pratica delle cure palliative: • Legge 22 dicembre 2017 n°219: pianificazione anticipata delle cure e dichiarazioni anticipate di trattamento.	2	Medico legale
8	Scelte difficili: • appropriatezza clinica: Evidence Base Medicine (EBM) e modulazione degli interventi, • nutrizione, • idratazione, • sedazione palliativa profonda continua: i sintomi refrattari	2	Medico Medico Palliativista
9	Focus su alcuni trattamenti infermieristici (utilizzo degli elastomeri, vie di somministrazione dei farmaci e liquidi, rilevazione di problemi di salute, interventi per garantire il comfort: stipsi da oppioidi, disfagia, mucosite orale).	3	Medico Infermiere
10	La relazione e la comunicazione con l'ospite, la famiglia.	2	Psicologo
11	La famiglia difronte alla morte, processi di adattamento, dinamiche familiari e modi di reagire di fronte al malato terminale. (Role play)	3	Psicologo
12	Incontri generali per informare i familiari sul progetto attivato dalla RSA	2 x 3 incontri=6	Medico e altri operatori
	Totale ore	33	

✓ PROGRAMMAZIONE EVENTI

Gli incontri verranno programmati periodicamente, prevedendo la distribuzione oraria in mezze giornate, possibilmente con un'edizione al mattino e una il pomeriggio, con orario da concordare. L'attività di docenza sarà preferibilmente assegnata ad esperti presenti nel C.S. o nella realtà della nostra ULSS.

ANALISI EPIDEMIOLOGICA

Revisione della documentazione sanitaria (cartelle cliniche cartacee e informatizzate) dalla quale ricavare un analisi epidemiologica dell'utenza accolta nel 2017.

In particolare saranno raccolti e analizzati i seguenti dati:

- ✓ Diagnosi d'ingresso
- ✓ Numero decessi: cause, luogo
- ✓ Ricorso al Pronto Soccorso e accessi in ospedale
- ✓ Visite specialistiche
- ✓ Consumo antibiotici, oppioidi, analgesici, antipsicotici, sedativi
- ✓ Utilizzo di farmaci somministrati nelle ultime due settimane di vita
- ✓ Ricorso a procedure invasive quali sondino naso gastrico, PEG, infusione endovenosa, ipodermoclisi
- ✓ Rilevazione del dolore
- ✓ Utilizzo pompa elastomerica – sedazione palliativa
- ✓ Utilizzo di Ossigenoterapia

Raccolta dati relativa all'anno 2018 per gli ospiti selezionati:

- ✓ Diagnosi d'ingresso
- ✓ Tempi di permanenza in struttura prima della morte
- ✓ Uso di analgesici (paracetamolo, FANS, oppioidi).
- ✓ Uso di antibiotici
- ✓ Monitoraggio dei Parametri Vitali
- ✓ Monitoraggio del Nurturing Touch
- ✓ Ricorso a procedure invasive quali PEG, Sondino naso gastrico, PEG, infusione endovenosa, ipodermoclisi.
- ✓ Ricorso al Pronto Scoccorso e accessi ospedale
- ✓ N° di visite specialistiche/N° di richieste d'intervento
- ✓ N° di visite del medico palliativista/ N° di richieste d'intervento
- ✓ Rilevazione del dolore e dei segni di morte imminenti
- ✓ Utilizzo pompa elastomerica – sedazione palliativa
- ✓ Causa del decesso

✓ CONFRONTO DATI (PRE E POST)

a- Rilevazione dolore con schede apposite

b- Distribuzione soggetti trattati con analgesici (divisi per macrocategorie)

c- Cause di decesso

d- Luogo del decesso

e- Utilizzo di farmaci somministrati nelle ultime due settimane di vita

f- Utilizzo di pompa elastomeri -Sedazione palliativa

h- Questionario di valutazione della qualità percepita (inizio somministrazione del questionario ai pazienti arruolati nel 2018 e confronto con i questionari raccolti negli anni 2019-20)

In itinere: diario sanitario, scheda cartacea di raccolta PV e riunioni d'equipe

INDICATORI DI PROCESSO E DI ESITO

OBTV	azioni	responsabilità	Indicatori di processo e di esito. (*IP* – IE)
1	Il MMG della struttura partecipa alla struttura del progetto	Direttore di Distretto	*IP*: co-realizzazione del progetto
		Direttore di Distretto	IE. Il MMG della struttura aderisce e partecipa alla realizzazione del progetto
2	Scegliere e introdurre modalità di valutazione: ✓ la domanda sorprendente ✓ scale di valutazione validate.	Operatori CSA. Medico CSA.	*IP*:sono identificati, presenti e usati i criteri di valutazione.
	Formare gli operatori a valutare l'ospite e a formulare un giudizio.	Operatori CSA. Medico CSA.	*IP*: i dati di valutazione sono riportati nella cartella clinica.
	Il medico del CSA si avvale dello specialista ospedaliero e del medico palliativista per la valutazione dell'ospite.	Medico CSA. Specialista ospedaliero. Palliativista. Direttore Ospedale. Direttore Distretto.	*IP*: esiste un modulo di richiesta per lo specialista e per il Palliativista. Esiste un modulo di autorizzazione all'accesso degli specialisti in C.S.A.
	Valutare gli ospiti all'ingresso in struttura e ogni sei mesi.	Medico CSA.	IE: esiste una lista di pazienti individuati.
3	Formalizzare una modalità di segnalazione alla COT e al Punto Unico di Accesso (PUA) e all' Unità Operativa di Cure Palliative dei pazienti individuati.	Responsabile COT/PUA. Caposala CSA. Coordinatore di percorso ospedaliero. Caposala UOCP.	*IP*: è presente un modulo per la segnalazione dei pazienti alla COT/PUA e all'UOCP.
	Segnalare alla COT/PUA e all' Unità Operativa di Cure Palliative i pazienti individuati.	Medico CSA.	IE: tutti i pazienti individuati sono segnalati.
OBTV	azioni	responsabilità	Indicatori
4	Il Direttore del Distretto e il Direttore dell'Ospedale informano gli specialisti ospedalieri sulla necessità di effettuare le UVMO/UVMD per i pazienti da avviare alle cure palliative.	Direttore ospedaliero. Direttore del distretto.	*IP*: verbale di riunione e direttive del Direttore dell'Ospedale.
	La COT/PUA istruisce l'UVMO/UVMD.	Responsabile COT/PUA.	*IP*: tutti i pazienti segnalati alla COT/PUA sono sottoposti a UVMO/UVMD.
	L' UVMO/UVMD formula il Piano Assistenziale Individuale e assegna il paziente alle Cure Palliative di Base o alle Cure Palliative Specialistiche.	Responsabile UVMD	IE: il PAI viene riportato in cartella per ogni paziente sottoposto a UVMO/UVMD

5	Il medico palliativista e il medico della R.S.A. effettuano con cadenza bimestrale una rivalutazione dei pazienti inseriti nel progetto di cure palliative di base.	Medico C.S.A. Medico palliativista	*IP*: La valutazione viene riportata in cartella clinica.
	Il medico C.S.A. attiva le C.P. specialistiche al peggioramento dell'ospite.	Medico C.S.A. Medico palliativista	IE: il medico Palliativista e/o altro personale dell'UCP accede alla C.S.A.
	Il Direttore di Distretto norma la modalità d'accesso del medico palliativista e/o altro personale dell' UOCP al C.S.A.	Direttore di Distretto	IE: il medico Palliativista e/o altro personale dell'UCOP accede al C.S.A
6	Il Direttore Ospedaliero norma la modalità d'accesso del medico specialista ospedaliero al C.S.A.	Direttore di Ospedale	IE: il medico specialista ospedaliero accede al C.S.A
7	Implementare l'uso di scale di valutazione dei sintomi e in particolare del sintomo dolore.	Medico CSA. Caposala CSA.	IE: sono individuate, scelte e presenti in cartella clinica scale per la valutazione dei sintomi. La cartella clinica riporta la registrazione della valutazione del sintomo.
	Implementare ed applicare procedure e tecniche per il controllo dei sintomi e per la gestione della fase terminale della vita: almeno 3 procedure/anno	Tutti gli operatori dei CSA a seconda delle rispettive competenze.	IE: sono presenti almeno 3 procedure esecutive per il trattamento dei sintomi.
	Migliorare l'uso dei farmaci in particolare i farmaci antalgici.	Medico CSA.	IE: esiste una procedura per la scelta e l'uso dei farmaci antalgici. Aumenta il consumo di oppiacei e si riduce l'uso dei FANS.
	Ridurre il ricorso agli accessi al pronto soccorso.	Medico CSA. Medico Palliativista Specialista. Ospedaliero. PAI.	IE: sono diminuiti del 10% gli accessi al pronto soccorso rispetto al 2017.
	Ridurre il ricorso al ricovero ospedaliero, favorendo la permanenza dell'ospite al proprio domicilio, ovvero in CSA.	Medico CSA. Medico Palliativista Specialista. Ospedaliero. PAI.	IE: sono diminuiti del 10% i ricoveri ospedalieri rispetto al 2017.
	Ridurre il n° di decessi in ospedale.	Medico CSA. Medico Palliativista Specialista. Ospedaliero. PAI.	IE: sono diminuiti del 10% i decessi in ospedale rispetto al 2017.

8	Formare tutto il personale.	Direttore CSA.	IP: n° eventi formativi effettuati. % di personale per ogni categoria che ha partecipato alla formazione.
	Il personale applica quanto viene appreso durante la formazione.	Caposala CSA.	IE: sono presenti e applicate le procedure di rilevamento e trattamento dei sintomi.
9	Condividere con il paziente competente e con i famigliari dei pazienti non competenti il programma di interventi.	Operatori CSA secondo le proprie competenze.	IE: registrazione in cartella del colloquio
	Attuare incontri di informazione con i famigliari.	Operatori CSA secondo le proprie competenze. Caposala CSA.	IE: n° di incontri effettuati. Verbali degli incontri.
10	Produrre la scheda dei dati da raccogliere per i deceduti del 2017 secondo quanto previsto nella sezione "analisi epidemiologica".	Caposala CSA Operatori CSA.	IE: esiste la scheda raccolta dati per i deceduti 2017.
	Produrre la scheda dei dati da raccogliere per i pazienti inseriti in un percorso di cure palliative nel 2018 secondo quanto previsto nella sezione "analisi epidemiologica".	Caposala CSA Operatori CSA.	IE: esiste la scheda raccolta dati per i pazienti inseriti in un percorso di cure palliative nel 2018.
	Effettuare un confronto fra i dati del 2017 e del 2018.	Rete Locale di Cure Palliative	IE: i risultati sono valutati e pubblicati.
	Presentare la relazione critica all'Azienda	Rete Locale di Cure Palliative	IE: l' Azienda è in possesso della relazione

COSTI DI INVESTIMENTO

C.S.A BRANDALISE DI FELTRE

INTERVENTI	ORE	COSTO ORARIO	COSTO TOTALE ANNUO	
Formazione dipendenti Glicine + Giardino	11/12 ore x 45 dip			
Raccolta dati 2017 +2018 e elaborazione	80 ore			
Supporto psicologico familiari	5 ore/mese			
Infermiere per supporto psicologico familiari e ospiti	10 ore a settimana			
Supporto aggiuntivo del medico di struttura durante il percorso sia per i dipendenti che per i familiari	da definire			
Poltrone relax	2			
			TOTALE	**€ 35.000,00**

A.P.S.P. "VALLE DEL VANOI"

INTERVENTI	ORE	COSTO ORARIO	COSTO TOTALE ANNUO
Costo dipendenti Formazione	20 ore x n.43 dip= 860		
Costo risorsa per raccolta/elaborazione dati Infermiere	72 ore		
Supporto psicologo libero professionista per i familiari	36 ore annue (3 ore al mese)		
Supporto aggiuntivo del medico di struttura durante il percorso sia per i dipendenti che per i familiari	60 ore annue (2 ore in più per ogni decesso, previsione 30 decessi)		
Incontri informativi per i familiari	6 ore annue (3 incontri per 2 ore)		
Supporto infermieristico durante il percorso sia per i dipendenti che per i familiari	15 ore in più da utilizzare per ogni utente in fine vita (previsti 30) = tot. 450		
Acquisto poltrona relax a disposizione del familiare durante l'assistenza	Poltrona reclinabile dotata di ruote		
TOTALE			**€ 35.000,00**

ALTRI COSTI .

INTERVENTI	ORE	COSTO ORARIO	COSTO TOTALE ANNUO
Costo per docenti per formazione	11/12 ore annue di formazione ripetute per 4 volte		
Altri costi: • Medico fiduciario Mano Amica • Infermiere con compiti di supporto al medico fiduciario • Interventi finalizzati a garantire gli interventi presso i C.S.A. da parte del nucleo di cure palliative e del personale delle strutture specialistiche (neurologia, cardiologia, pneumologia, medicina	3/6 mese secondo necessità. 2/3 ore settimana secondo necessità.		

generale, geriatria, nefrologia/dialisi,….). • Ogni altro costo per risorse umane, tecnologiche e materiali non preventivato che abbia a rendersi necessario nel corso della sperimentazione.			

COPERTURA COSTI INVESTIMENTO:

Il Costo di investimento per la realizzazione del progetto viene stimato complessivamente pari ad euro 140.000 e sarà finanziato con contributo straordinario dell' Associazione Mano Amica-Onlus di Feltre.

CONCLUSIONI

Questo Progetto, contenente aspetti anche di carattere innovativo, sarà uno strumento a supporto delle decisioni clinico-assistenziali per contribuire a cambiare gli atteggiamenti e a migliorare le pratiche nei confronti dei malati nella fase finale della loro vita in contesto dei CSA.

Alla fine di questo percorso e sulla base dei risultati raggiunti presso le due strutture, sarà possibili estendere il progetto in tutti i CSA per Anziani non autosufficienti, anche al fine di dare un forte impulso all'organizzazione di una rete di cure palliative a livello provinciale. (Belluno – Trento).

RINGRAZIAMENTI

Si desidera esprimere un ringraziamento speciale all'Associazione Mano Amica di Feltre che ha fortemente voluto e creduto in questo importante progetto finanziando i totali costi per la sua realizzazione, alla direzione dell'ULSS 1 Dolomiti di Feltre per la volontà di aumentare, attraverso la concretizzazione del progetto, la capacità del territorio dell'intera provincia di Belluno e della Comunità di Primiero, quest'ultima in relazione alla convenzione in essere con l' APSS di Trento, di far fronte ai bisogni di cure palliative del malati complessi con malattie cronico degenerative avanzate nelle strutture residenziali sanitarie assistenziali.

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