



Sri Lakshmi Narayana Institute of Medical Sciences

Date: 03.11.2021

From
Dr. Nithianandam
Professor and Head,
Department of Anaesthesia
Sri Lakshmi Narayana Institute of Medical Sciences
Bharath Institute of Higher Education and Research
Puducherry

To
The Dean,
Sri Lakshmi Narayana Institute of Medical Sciences
Puducherry

Sub: Request for Permission to conduct value-added course: Palliative Care

Dear Sir,

With reference to the subject mentioned above, the department proposes to conduct a value-added course titled: Palliative Care for undergraduates from January 2022. We solicit your kind permission for the same.

Kind Regards

Dr. NITHIANANDAM. S

FOR THE USE OF DEANS OFFICE

Names of Committee members for evaluating the course:

The Dean: Dr JAYAKUMAR

The HOD: Dr.NITHIANANDAM. S

The Expert: Dr SUJARITHA

The committee has discussed about the course and is approved.


Dean

DEAN
SRI LAKSHMI NARAYANA INSTITUTE OF MEDICAL SCIENCES
OSUDU, AGARAM VILLAGE,
KOCDAPAKKAM POST,
PUDUCHERRY - 605 502


Subject Expert

DEPARTMENT OF ANAESTHESIOLOGY
SRI LAKSHMI NARAYANA INSTITUTE OF MEDICAL SCIENCES
OSUDU, KUDAPAKKAM, PUDUCHERRY - 605 502


HOD

Head of Dept. Anaesthesiology,
Sri Lakshmi Narayana Institute of Medical Sciences
Osudu, Kudapakkam, Puducherry - 605 502



OFFICE OF THE DEAN

Sri Lakshmi Narayana Institute of Medical Sciences

OSUDU, AGARAM VILLAGE, VILLIANUR COMMUNE, KUDAPAKKAM POST,
PUDUCHERRY - 605 502.

[Recognised by Medical Council of India, Ministry of Health letter No. U/12012/249/2005-ME (P -II) dt. 11/07/2011]
[Affiliated to Bharath University, Chennai - TN]

Circular

20.12.2021

Sub: Organizing Value-added Courses: Palliative Care- reg

With reference to the above mentioned subject, it is to bring to your notice that Sri Lakshmi Narayana Institute of Medical Sciences, **Bharath Institute of Higher Education and Research** is organizing “**PALLIATIVE CARE**” course Jan 2022. The course content is enclosed below.”

The application must reach the institution along with all the necessary documents as mentioned. The hard copy of the application should be sent to the institution by registered/ speed post only so as to reach on or before 27/12/2021. Applications received after the mentioned date shall not be entertained under any circumstances.

Encl: Copy of Course content

Dean

DEAN
SRI LAKSHMI NARAYANA INSTITUTE OF MEDICAL SCIENCES
OSUDU, AGARAM VILLAGE,
KODAPAKKAM POST,
PUDUCHERRY - 605 502

COURSE PROPOSAL

Course Title: PALLIATIVE CARE

Course Objective:

- 1.To enable the students to learn what is palliative care and who are the people requiring it. It also teaches them about various components included in it.
2. To learn about the recent advances made in the field of palliative care.

Course Outcome:

On successful completion of the course the students will have thorough understanding of end of life care.

Course Audience: II year MBBS students

Course Coordinator: Dr S NITHIANANDAM

Course Faculties with Qualification and Designation:

1. Dr S Nithianandam-Professor And HOD
2. Dr Sujaritha- Assistant Professor

Course Curriculum/Topics with schedule (Min of 30 hours)

S.No	Date	Topic	Time	Hours	Faculty
1	07.01.2022	Introduction, principles and practice	2-4PM	2	Dr Nithianandam
2	21.01.2022	Cancer and chronic pain	2-4PM	2	Dr Sujaritha
3	28.01.2022	History and evaluation	2-4PM	2	Dr Nithianandam
4	04.02.2022	Presentation and symptoms	2-4PM	2	Dr Sujaritha
5	11.02.2022	Management	2-4PM	2	Dr Nithianandam
6	18.02.2022	Interventions in PC	2-4PM	2	Dr Sujaritha
7	25.02.2022	Prevention of symptoms	2-4PM	2	Dr Nithianandam
8	04.03.2022	Symptoms and management in Pc	2-4PM	2	Dr Sujaritha
9	11.03.2022	Communication	2-4PM	2	Dr Nithianandam
10	18.03.2022	Ethical issues	2-4PM	2	Dr Sujaritha
11	25.03.2022	Pc in non malignant patients	2-4PM	2	Dr Nithianandam
12	01.04.2022	Pc in elderly patients	2-4PM	2	Dr Sujaritha
13	08.04.2022	Pc in pediatric patients	2-4PM	2	Dr Nithianandam
14	22.04.2022	Psycho social issues and management	2-4PM	2	Dr Sujaritha
15	29.04.2022	Approach to end of life	2-4PM	2	Dr Nithianandam

REFERANCES

- 1) R Sean Morrison, Diane E Meier, New England Journal of Medicine 350(25),2582-2590,2004.
- 2) BernardLo, Timothy Quill, James Tulsky, Annals of Internal Medicine 130(9),744-749,1999.
- 3) Anational strategy for palliative care, Diane E Meier, Anthony L Back, Amy Berman, Susan D Block, Janet M Corrigan, R Sean Morrison, Health affairs 36(7),1265-1273,2017

VALUE ADDED COURSE

1. Name of the program & Code

PALLIATIVE CARE, ANAES 04

2. Duration & Period

30 hrs: Jan 2022

3. Information Brochure and Course Content of Value Added Courses

Enclosed as Annexure- I

4. List of students enrolled:

Enclosed as Annexure- II

5. Assessment procedures:

Multiple choice questions- *Enclosed as Annexure- III*

6. Certificate of Participation:

Enclosed as Annexure- IV

7. No. of times offered during the same year:

1 Time JAN 2022

8. Year of discontinuation: 2022

9. Summary report of each program year-wise

Value Added Course- Jan- June 2017					
Sl. No	Course Code	Course Name	Resource Persons	Target Students	Strength & Year
1	ANAES 04	PALLIATIVE CARE	DR. SUJARITHA	II MBBS	30

10. Course Feed Back

Enclosed as Annexure- V

RESOURCE PERSON
DEPARTMENT OF ANAESTHESIOLOGY
SRI LAKSHMI NARAYANA INSTITUTE
OF MEDICAL SCIENCES
OSUDU, KUDAPAKKAM, PUDUCHERRY-605 502

COORDINATOR

Dr S NITHIANANDAM

Head of Dept. Anaesthesiology
Sri Lakshmi Narayana Institute of Medical Sciences
Osudu, Kudapakkam, Puducherry - 605 502.

Annexure I

Palliative and end of life care

Cancer and chronic pain

Pain in cancer may arise from a tumor compressing or infiltrating nearby body parts; from treatments and diagnostic procedures; or from skin, nerve and other changes caused by a hormone imbalance or immune response. Most **chronic (long-lasting) pain** is caused by the illness and most acute (short-term) pain is caused by treatment or diagnostic procedures. However, **radiotherapy**, surgery and **chemotherapy** may produce painful conditions that persist long after treatment has ended.

The presence of pain depends mainly on the location of the cancer and the **stage** of the disease.^[1] At any given time, about half of all people diagnosed with **malignant cancer** are experiencing pain, and two thirds of those with advanced cancer experience pain of such intensity that it adversely affects their sleep, mood, social relations and **activities of daily living**.^{[1][2][3]}

With competent management, cancer pain can be eliminated or well controlled in 80% to 90% of cases, but nearly 50% of cancer patients in the developed world receive less than optimal care. Worldwide, nearly 80% of people with cancer receive little or no pain medication.^[4] **Cancer pain in children** and in people with **intellectual disabilities** is also reported as being under-treated.^[5]

Chronic pain: Pain (an unpleasant sense of discomfort) that persists or progresses over a long period of time.

Chronic pain is pain that is ongoing and usually lasts longer than six months. This type of pain can continue even after the injury or illness that caused it has healed or gone away. Pain signals remain active in the nervous system for weeks, months or years. Some people suffer chronic pain even when there is no past injury or apparent body damage. Chronic pain is linked to conditions that include:

- Headache.
- Arthritis.
- Cancer.
- Nerve pain.
- Back pain.
- Fibromyalgia.

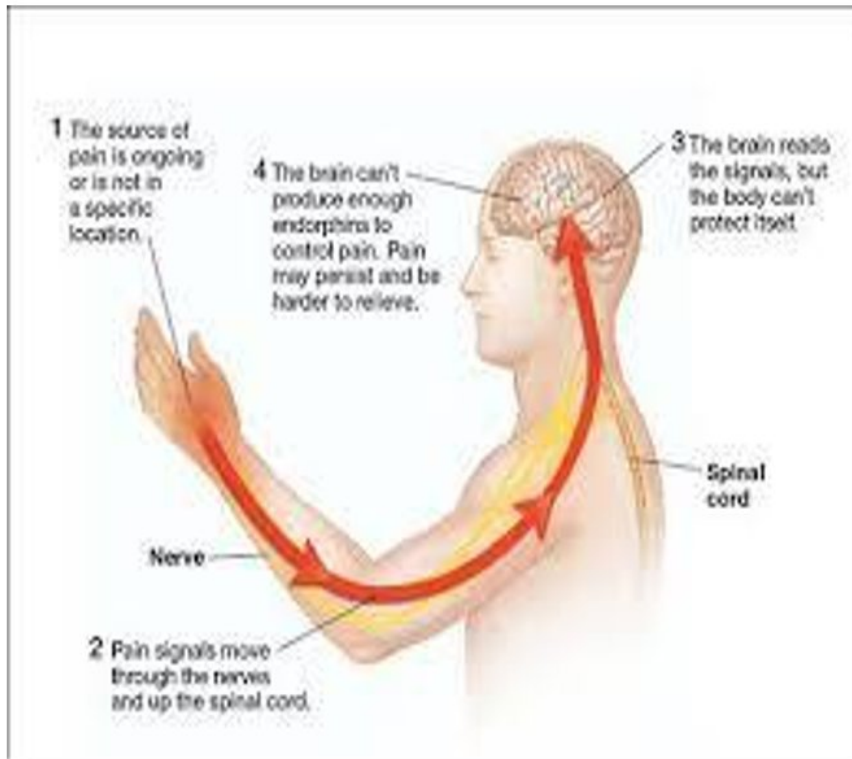
If you have chronic pain, the stress affects the body, producing physical conditions like:

- Tense muscles.
- Limited ability to move around.
- A lack of energy.
- Changes in appetite.

Chronic pain also causes emotional effects, including:

- Depression.
- Anger.

- Anxiety.
- Fear of re-injury. This fear could limit your ability to return to work or leisure activities.



PALLIATIVE AND END OF LIFE CARE

HISTORY AND EVOLUTION

The development by the second half of the twentieth century of new technologies and effective specific treatments for disease still left much suffering unaddressed. As Professor Patrick Wall wrote in 1986, 'Symptoms were placed on one side and therapy directed at [them] was denigrated'¹.

In the same vein, when Aneurin Bevan introduced the National Health Service Bill to Parliament, he stated that he would 'rather be kept alive in the efficient if cold altruism of a large hospital than expire in a gush of sympathy in a small one'².

But what if no cure was possible and the end of life was inevitable? Referring particularly to the hospice movement, Wall added that 'The old methods of care and caring had to be rediscovered and the best of modern medicine had to be turned to the task of new study and therapy specifically directed at pain'. Care, matched with an increasingly sound evidence base, was by then underpinned by the concept of 'total pain'—defined in 1964 as including not only physical symptoms but also mental distress and social or spiritual problems³.

This approach met ready audiences among nursing and medical students during lectures or in articles, as well as social workers and more gradually among senior members of the medical profession.

AN EVIDENCE BASE

During the 1950s three important surveys of end-of-life care were undertaken. In 1952 a report based on the observations of district nurses throughout the UK of some 7050 cases, published by the Marie Curie Memorial Foundation⁴, revealed appalling conditions of suffering and deprivation among many patients dying of cancer at home. By 1960, Glyn Hughes had conducted a nationwide survey for the Gulbenkian Foundation⁵. This included widespread consultations, 300 site visits and contacts with 600 family doctors. Conditions in charitable homes were judged seriously inadequate, with deficiencies in financial support and

staffing, and a large proportion of the nursing homes visited were deemed 'quite unsuited—and in some cases amounting to actual neglect when measured by standards that can reasonably be expected'. Hughes noted 'a serious gap in the National Health Service with an unanswered question of where and by whom the elderly terminally ill would be cared for'. Finally, a unique detailed study of the physical and mental distress of the dying was published by John Hinton in 1963⁶. His observations from the wards of a London teaching hospital showed that much suffering remained unrelieved and also how most patients were well aware of their prognosis despite the lack of information normally given at that time.

A PERSONAL HISTORY

In 1948, after experience of wartime nursing in the absence of nearly all our modern pharmacology, and as a social worker among patients and families devastated by unrelieved pain in terminal cancer, I encountered the Polish Jew whose few poignant words proved a powerful catalyst of a new world-wide movement. His statement 'I will be a window in your Home' gave a challenge to openness of all kinds; 'I want what is in your mind and in your heart', set scientific enquiry alongside personal encounter; his very personal journey, into peace, gave the demand for space for freedom of spirit in facing the mystery of death.

A hope of returning to nursing in this field was countered by the surgeon Norman Barrett who said 'Go and read medicine. It's the doctors who desert the dying and there's so much to be learned about pain. If you don't do it properly you'll only be frustrated, and they won't listen to you'.

There followed seven years of voluntary work as a nurse in an early 'home' which gave me the first experience of the effectiveness of small regular doses of oral morphine. This was combined with a medical training during the pharmacological explosion of the 1950s and led to seven years of clinical care and research at St Joseph's Hospice from 1958. The introduction of the detailed recording of an oral and regular regimen, and the development of symptom control with the drugs becoming available, led to the change expressed by one of the nuns nursing there as 'from painful to pain free'. The basic methodology of listening and tape-recording, coupled with a commitment to the day-to-day care of patients with advanced malignant disease in the 45 beds, was the basis of the analysis of 1100 cases in a punch-card system (this being the precomputer age). As in Hinton's seminal paper, patient's comments were used as illustrations—'It seemed that all of me was wrong'; 'It was all pain, but now it's gone and I'm free'; 'They used to want me to hold on a bit longer—I was sweating with the pain—but now I feel so calm'.

A DEMONSTRATION PROJECT

On the basis of the experience and evidence described above, a project to show how to address the proven gap in National Health Service provision was launched as a new charity. From 1959 onwards detailed memoranda presenting 'the need' and 'the scheme' were circulated to likely advisers and supporters. A steering group and countless correspondents were drawn into a rigorous discussion of the challenges and possibilities. Medical, social and spiritual issues had to be addressed before planning and fund-raising could begin.

The medical foundation was based on the clinical experience and research at St Joseph's Hospice and all that had led up to it, alongside extensive reading in the library of the Royal Society of Medicine. Anecdote heavily outweighed studies but, by 1967, 184 references had been assembled. The work at the hospice had been enthusiastically welcomed because it had been possible to demonstrate that patients could be free of pain and still alert, responsive and remaining themselves. The Londoners from the disadvantaged East End joined gladly in the medical student teaching rounds. Their stories and the growing body of evidence that tolerance and drug dependence did not develop were the basis of lectures and articles^{7,8}.

These beginnings pointed to work that would be conducted when the new hospice was finally built and opened for inpatient and home care and for research into the relief of distress. The methods used were those that could be widely transferable, with multiprofessional education planned to rely heavily on clinical experience.

The spiritual needs of patients and families struggling with what might seem pointless suffering were a greater challenge. Fear and grief were often inarticulate. How could we make sure the hospice was not seen as a 'death house'? How would the earlier traditions of the religious charities be interpreted in an increasingly secular world? In the end, this new charity was based on extremely broad spiritual foundations. That 'There shall be a Chapel, available for Christian worship' emphasized that there would be no pressure on anyone, staff or patient, to enter it and no bar to other faiths doing so.

Finally, how to support the staff whose care had to be of a nature that would reach the most hidden places of distress? It was anticipated that

there would be a more flexible commitment than among the nuns at St Joseph's Hospice but with some form of community ethos. After much debate, I wrote, 'I think we will know when we get there' and, later, 'We are a community of the unlike'. By the end of 1960, these issues had been addressed and a basis laid for future development.

St Christopher's Hospice opened in 1967 with a building for 54 patients, a 16-bed residential wing for the elderly, a nursery for staff children and a planned bereavement service. Home care, which had been incorporated in the plans from the beginning, started nearly two years later. Both the early drug studies and the home-care outreach were funded by the National Health Service. Currently, nearly ten times more patients are being cared for at home than as inpatients.

SPREADING CONTACTS

The thousands of letters written during the years 1959-67, as these ideas were developed, are now preserved in extensive indexed archives. Correspondence with the Director of the National Cancer Institute at Bethesda, with the foreign desk of the American Cancer Society and with many others are housed in this comprehensive set of records. An eight-week tour of the United States in 1963 led to many links. Contact was made with Beecher, Houde and Wallenstein and other pain researchers, with the psychiatrist Avery Weisman and with social worker Ruth Abrams in Boston, to name a few. The continuing links and visits between the USA and the UK have proved enormously stimulating and helpful. Three sabbatical visits to St Christopher's Hospice in the early years led to the setting up in Connecticut, New York and Montreal of teams in three

different developments of modern palliative care. These were home-care teams, hospital-care teams without specific back-up beds, and a unit with a consulting team in a teaching hospital. All three patterns have been adopted widely around the world.

WHERE DID WE GO RIGHT?

First, I make no apology for identifying as a correct starting-point the methodology of simple listening, recording and analysing. As Wall wrote in 1997, 'Palliative care has succeeded in the face of two common myths which were shared by patients and doctors [of drug dependence and tolerance] swept aside by precise and convincing observation'⁹. The demonstration of appropriate, scientifically based and patient-centred treatment, first demonstrated in St Joseph's Hospice and later in St Christopher's Hospice, eventually led to the establishment of a recognized specialty in 1987 in Australia, New Zealand and the UK. The focus on cancer pain, which could be convincingly researched and published, led to a developing evidence base.

Secondly, the fostering of links with basic and clinical pain researchers and other allied workers on both sides of the Atlantic, through voluminous correspondence since 1960 and numerous visits, provided stimulating interchanges. Without these, other international links in palliative care would not have developed.

Thirdly, efforts to change attitudes to end-of-life care were, and still are, based on rigorous philosophical, political and spiritual discussions. From the beginning the emphasis was on 'living until you die'. The substantial

body of indexed archives, attributable to a jackdaw-like character, offers material for a fruitful and stimulating study.

WHERE DID WE GO WRONG?

On the minus side, over-enthusiastic lectures tended to arouse not only enduring commitments but also a tendency to perfectionism and élitism. Failures teach us more than successes and were not always faced in the early days.

Secondly, the focus on the diagnosis of cancer sometimes hindered the acceptance of challenges in other areas of need, HIV/AIDS being a case in point. But how do we balance need, skills and resources?

Thirdly, although we looked to a research and educational base, we were too slow in establishing full academic rigour (and still have some way to go). Indeed, learning and discovery must surely be endless.

Finally, the concentration in a building, at least in the UK, tended to outweigh the emphasis on home care. Palliative care is a philosophy based not on physical facilities but on attitudes and skills, as the many interpretations around the industrialized and developing world show forcefully.

FOR THE FUTURE

There remains a clamant need to address attitudes to end-of-life care among the professions, the public and the media. The losses of parting cannot be removed but their devastating effects can be ameliorated. For this we must give attention to the whole person, with all the insights the humanities can give us.

We need to focus more on the discrepancy between the developed and developing worlds in terms of medical care and research, epidemiological and clinical. Validated tools for assessing quality of life should be more widely used with this challenge in mind.

Psychological issues for patients and families should be studied, with recognition of profound (though often unarticulated) spiritual and existential distress. Academic centres with multiprofessional teams have the potential to develop recognized standards. These should be offered as part of the ongoing commitment to every person in need of care for progressive disease, and should incorporate the same urge for exploration as characterized at the earlier stages. Our common humanity demands no less.

Palliative and end of life care

Introduction

The World Health Organisation defines palliative care as “the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.”

Palliative care is necessarily multidisciplinary. It is unrealistic to expect one profession or individual to have the skills to make the necessary assessment, institute the necessary interventions, and provide ongoing monitoring.

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

Addressing suffering involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling. It offers a support system to help patients live as actively as possible until death.

Palliative care is explicitly recognized under the human right to health. It should be provided through person-centered and integrated health services that pay special attention to the specific needs and preferences of individuals.

Palliative care is required for a wide range of diseases. The majority of adults in need of palliative care have chronic diseases such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%). Many other conditions may require palliative care, including kidney failure, chronic liver disease, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies and drug-resistant tuberculosis.

Pain and difficulty in breathing are two of the most frequent and serious symptoms experienced by patients in need of palliative care. For example, 80% of patients with AIDS or cancer, and 67% of patients with

cardiovascular disease or chronic obstructive pulmonary disease will experience moderate to severe pain at the end of their lives. Opioids are essential for managing pain.

Opioids can also alleviate other common distressing physical symptoms including breathlessness. Controlling such symptoms at an early stage is an ethical duty to relieve suffering and to respect a person's dignity.

Insufficient access to palliative care

Each year an estimated 40 million people are in need of palliative care, 78% of whom live in low- and middle-income countries. For children, 98% of those needing palliative care live in low- and middle-income countries with almost half of them living in Africa.

Worldwide, a number of significant barriers must be overcome to address the unmet need for palliative care:

- national health policies and systems often do not include palliative care at all;
- training on palliative care for health professionals is often limited or non-existent; and
- population access to opioid pain relief is inadequate and fails to meet international conventions on access to essential medicines.

According to a WHO survey relating to noncommunicable diseases conducted among 194 Member States in 2019: funding for palliative care was available in 68% of countries and only 40% of countries reported that the services reached at least half of patients in need (1).

The International Narcotics Control Board found that in 2018, 79 per cent of the world's population, mainly people in low- and middle-income countries, consumed only 13 per cent of the total amount of morphine used for the management of pain and suffering, or 1 per cent of the 388 tons of morphine manufactured worldwide. Although that was an improvement over 2014, when 80 per cent of the world's population consumed only 9.5 per cent of the morphine used for the management of pain and suffering, the disparity in the consumption of narcotic drugs for palliative care between low- and middle-income countries and high-income countries continues to be a matter of concern (2).

Other barriers to palliative care include:

- lack of awareness among policy-makers, health professionals and the public about what palliative care is, and the benefits it can offer patients and health systems;
- cultural and social barriers, such as beliefs about death and dying;
- misconceptions about palliative care, such as that it is only for patients with cancer, or for the last weeks of life; and
- misconceptions that improving access to opioid analgesia will lead to increased substance abuse.

National health systems are responsible for including palliative care in the continuum of care for people with chronic and life-threatening conditions, linking it to prevention, early detection and treatment programmes. This includes, as a minimum, the following components:

- health system policies that integrate palliative care services into the structure and financing of national health-care systems at all levels of care;
- policies for strengthening and expanding human resources, including training of existing health professionals, embedding palliative care into the core curricula of all new health professionals, as well as educating volunteers and the public; and a medicines policy which ensures the availability of essential medicines for managing symptoms, in particular opioid analgesics for the relief of pain and respiratory distress.

Palliative care is most effective when considered early in the course of the illness. Early palliative care not only improves quality of life for patients but also reduces unnecessary hospitalizations and use of health-care services.

Palliative care needs to be provided in accordance with the principles of universal health coverage. All people, irrespective of income, disease type or age, should have access to a nationally- determined set of basic health services, including palliative care. Financial and social protection systems need to take into account the human right to palliative care for poor and marginalized population groups.

As part of multidisciplinary teams, the nursing workforce should be trained in palliative care skills, especially those who work with patients with serious illness.

Specialist palliative care is one component of palliative care service delivery. But a sustainable, quality and accessible palliative care system

needs to be integrated into primary health care, community and home-based care, as well as supporting care providers such as family and community volunteers. Providing palliative care should be considered an ethical duty for health professionals.

Principles of palliative care

- Affirms life and regards dying as a normal process
- Neither hastens nor postpones death
- Provides relief from pain and other distressing symptoms
- Integrates the psychological and spiritual aspects of care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help patients' families cope during the patient's illness and in their own bereavement

Practice

Modern palliative care originated in the development of St Christopher's Hospice in London in 1967. Recognising the unmet needs of dying patients in hospital, Dame Cecily Saunders established the hospice and, with others, conceived of a comprehensive approach to dealing with the variety of symptoms and suffering often experienced by patients with progressive debilitating disease. Careful observation of the use and effects of morphine and similar drugs also originated at the hospice.

Palliative and end of life care

Presentation and symptoms

Pain

Many people worry about the comfort of their loved one and their level of pain as end of life nears.

Pain management is a key part of end of life and palliative care.

If pain is well managed, quality of life will be better. The person is likely to sleep better and have more energy during the day.

If they feel less pain, they can be more active, which also reduces the risk of complications.

We all feel discomfort in different ways and people experience pain differently.

Not all people who need palliative care suffer ongoing pain. Some people may feel uncomfortable if they feel sick, tired, worried or restless and this can result in feeling more pain.

The palliative care team and the person's GP aim to reduce the pain as much as possible.

Although there have been many advances in treatment of pain, it may not always be completely eliminated.

Nausea

Nausea is when a person feels the urge to vomit or just feels sick.

The cause of nausea can be related to the disease, medications, chemotherapy, radiotherapy, constipation or an imbalance of chemicals within the body

Constipation

Constipation occurs when a person does not open their bowels for several days longer than the usual time for this person.

This symptom can cause nausea, pain and tiredness. Constipation can occur due to decreased fluid intake, limited mobility, poor diet or the person's illness. It can also be a side effect of medication or some treatments. In most instances constipation can be prevented.

Fatigue

Fatigue is very common in people with life-limiting illness.

It is a feeling of weariness, tiredness, or lack of energy that does not go away when you rest.

People may feel fatigued in body or mind. Fatigue reduces the ability for people to be active, and can be frustrating and debilitating.

Possible causes are: lack of sleep low blood oxygen levels poor diet depression effect of chemotherapy or radiotherapy and infection.

Breathlessness

Breathlessness is an unpleasant feeling of having difficulty breathing.

It can be caused by lung disease, asthma, emphysema, chest infection, pressure from other body organs, or anxiety.

Palliative and end of life care

Management

Every person is different and symptoms experienced at end of life vary.

Some common symptoms are pain, constipation, nausea, tiredness, breathlessness, fatigue and delirium.

In most cases symptoms can be controlled to a comfortable level, but some symptoms may not disappear completely.

Relief of symptoms is one of the major aims of the palliative care team.

As a carer, you can help the person caring for by assisting them in recognising and managing their symptoms.

Only do this if you feel comfortable doing so and if your relative is happy for you to do so. Otherwise, contact a palliative care team member if you are concerned about symptom management.

[Go to:](#)

INTRODUCTION

Most patients with cancer experience symptoms, the prevalence and severity of which vary according to cancer type, stage, treatment(s), and comorbidities.¹⁻⁴ In advanced cancer, 35% to 96% of patients experience pain, 32% to 90% experience fatigue, and 10% to 70% experience breathlessness ([Fig 1](#)).²

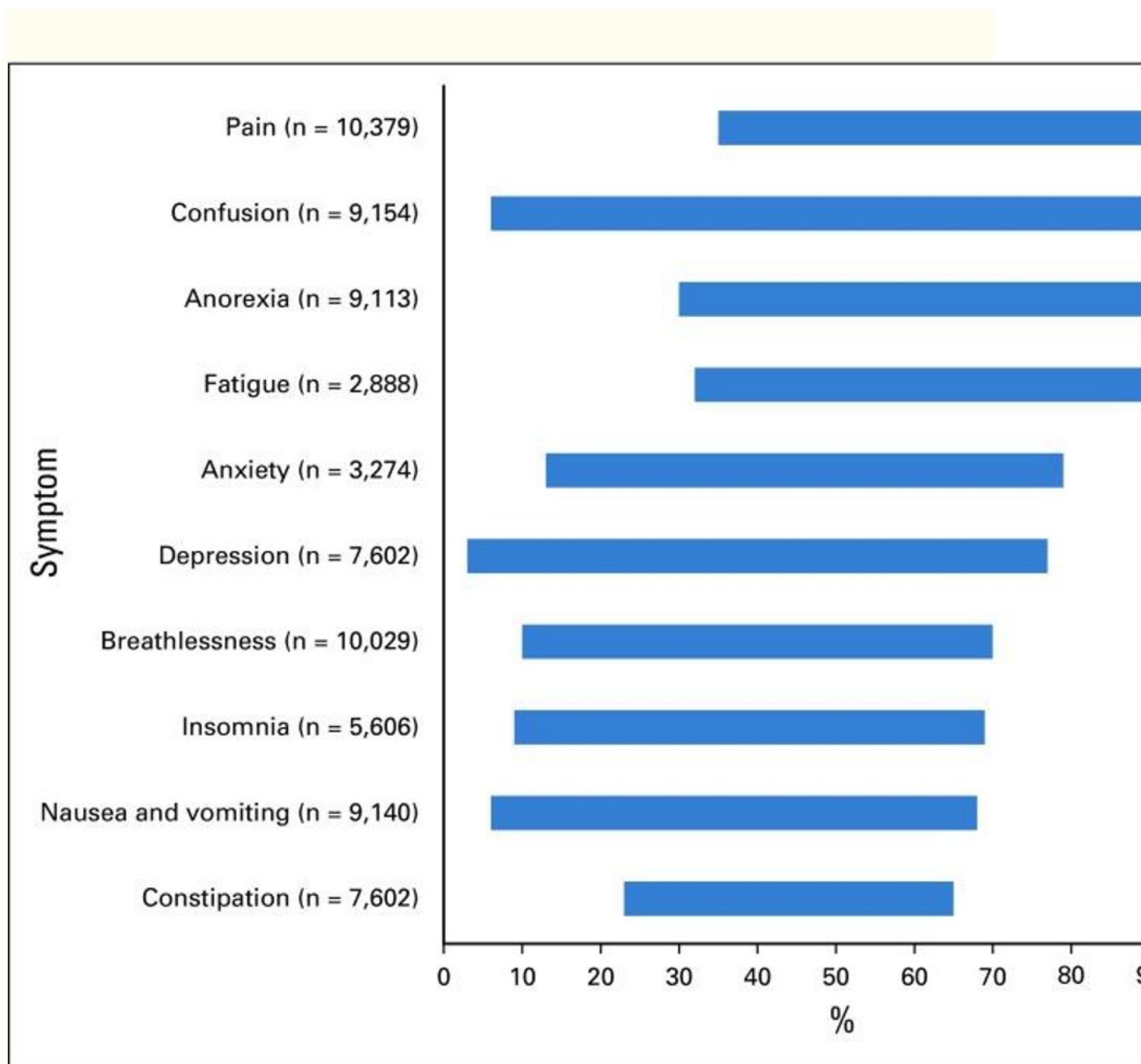


FIG 1.

Minimum-maximum symptom prevalence (%) for patients with cancer (n = total number of patients involved in the studies for each symptom). Adapted from systematic review findings of Solano et al.¹

Patients typically experience more than one symptom at any one time.⁵ Those with metastatic cancer and breathlessness (as a marker of advanced disease) have, on average, 14 symptoms.⁶ Grond et al⁵ found that 94% of those referred to a cancer pain clinic experienced additional symptoms, with 15% reporting at least five. Symptoms can be caused by the cancer itself, direct or indirect consequences of the cancer, early or late adverse effects of treatment, and/or comorbid conditions.⁷ The last two causes are becoming increasingly common as treatments advance and the population ages. Accurate symptom assessment and diagnosis are essential for effective treatment.⁸ Good symptom management is associated with improved patient and family quality of life,⁹⁻¹¹ greater treatment compliance,^{12,13} and may even offer survival advantages.¹³⁻¹⁷ Yet, despite these benefits, pain and other symptoms remain poorly managed and/or undertreated in many cases, highlighting the need for additional improvements in care.¹⁸⁻²⁰

This article provides a summary of symptom assessment tools and reviews the management of four common and distressing symptoms frequently experienced by patients with advanced cancer: pain, breathlessness, nausea and vomiting, and fatigue. We also discuss the role of palliative care in supporting a holistic approach to symptom management throughout the cancer trajectory.

SYMPTOM ASSESSMENT TOOLS

Many symptom assessment tools are available for patients with advanced cancer, as exemplified by a survey of palliative care professionals (n = 331), in which 99 tools for clinical practice and 94 for research were

identified.²¹ These assessment tools differ in various aspects, such as symptom selection, the inclusion of global quality-of-life questions, measurement of function, type of assessment scales (ie, visual analog v numeric rating scale), and validation for research and/or clinical practice. Commonly cited tools for both clinical practice and research are the Edmonton Symptom Assessment System Revised (ESAS-r),^{22,23} the Palliative Care Outcome Scale (POS),^{24,25} and the Palliative Performance Scale.²⁶

The incorporation of patient-reported outcome measures (PROMs) into routine clinical practice is supported by evidence that they improve symptom assessment and monitoring over time, help identify patients' unmet needs or concerns, and assist clinicians with decision making and treatment planning.²⁷⁻³¹ Examples of PROMs for patients with advanced cancer include the ESAS-r²³ and the POS.²⁵ The ESAS-r replaces the original ESAS that was first developed by Bruera et al²² in 1991. ESAS-r is a self-report tool, designed to capture multidimensional symptom profiles over time. It uses 11-point numeric rating scales to measure the intensity of nine symptoms (pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, shortness of breath), and includes the option of measuring an additional patient-specific symptom. ESAS-r is validated for self- and proxy-reporting, has guidance on interpreting its numeric rating scale,²³ and has transcultural adaptation for use in low- and middle-income countries.³²

The POS was initially developed in 1999 as a tool to measure the palliative care needs of patients and their families. It has 10 items covering physical symptoms (n = 2), psychological symptoms (n = 2), spiritual considerations

(n = 1), social needs (n = 4), and carer concerns (n = 1), with each item scored using a 0 to 4 (Likert) scale, with numeric and descriptive labels. The POS also includes a free text section, where patients are asked, “If any, what have been your main problems in the last three days?”³³ A number of adapted POS versions now exist, including those specific to certain populations, for example, MyPOS for patients with myeloma.³⁴ Transcultural adaptations are also available for more than 13 countries.^{35,36} All POS versions are validated for self- and proxy-reporting and have a clinical decision support tool to aid use.³⁷

For older patients with advanced cancer, Van Lancker et al³⁸ developed and validated the Assessment Symptoms Palliative Elderly, a 36-item instrument to assess symptom frequency and intensity. Although longer than ESAS-r and POS, the tool places a greater emphasis on assessing function, social symptoms, and psychological issues, all of which are prominent areas of concern for older patients with cancer.

Use of technology is likely to be an important and key component to implementing PROMs into routine clinical practice.³⁹ Examples where integration has been successful include home asthma telemonitoring systems⁴⁰ and Web-based support platforms for patients with insulin-dependent diabetes.⁴¹ In an oncology setting, Velikova et al⁴² found that regular repeated assessment of health-related quality of life of patients with cancer (using touch-screen computers in outpatient clinics) improved patients’ emotional well-being and resulted in more frequent discussions of chronic nonspecific symptoms. Similarly, in a randomized trial of 766 patients with metastatic cancer, Basch et al^{30,31} found that those receiving care incorporating routine patient-reported electronic monitoring of

symptoms had greater improvements in health-related quality of life (34% v 18%), fewer emergency department visits or admissions to hospital (34% v 41% and 45% v 49%, respectively), and longer quality-adjusted survival (mean, 8.7 months v 8.0 months) compared with those receiving usual care. In a study of patients with lung cancer, Denis et al⁴³⁻⁴⁵ investigated the E-MOSAIC intervention, which used real-time electronic monitoring of PROMs, with measures completed weekly by participants on a palm-based device (ClinicalTrials.gov identifier: [NCT00477919](https://clinicaltrials.gov/ct2/show/study/NCT00477919)). They found that weekly reporting of symptoms resulted in improved survival compared with those receiving usual care (median survival, 22.4 months v 16.7 months). Compared with the control group, those in the intervention group also had greater improvements in symptoms, communication, and coping, but not overall quality of life.⁴⁶

SYMPTOM MANAGEMENT

High-quality symptom assessment and management are fundamental to providing holistic, patient-centered care that results in positive outcomes for patients and their families. Despite their ubiquity, most symptoms experienced by patients with advanced cancer can be effectively managed using pharmacologic and/or nonpharmacologic approaches; symptom assessment and management is therefore an expected core skill of all clinicians involved in caring for patients with cancer. The following section reviews the latest evidence for the management of four symptoms commonly experienced by patients with advanced cancer: pain, breathlessness, nausea and vomiting, and fatigue.

Pain

Despite its ubiquity and the availability of management guidelines, more than 30% of patients with cancer receive inadequate analgesia for pain.⁴⁷ Identifying the pain modality (nociceptive, neuropathic, or combined) helps direct effective therapy, with the WHO analgesic ladder providing a therapeutic framework.⁴⁸

Nonpharmacologic treatments in the management of cancer pain include physical (massage, aromatherapy, transcutaneous electrical nerve stimulation, and acupuncture) and cognitive modalities (relaxation, distraction, and imagery exercises).⁴⁹ Evidence to support the effectiveness of aromatherapy,⁵⁰ transcutaneous electrical nerve stimulation,⁵¹ and acupuncture⁵² for reducing pain intensity in patients with cancer is lacking. For massage, study findings have been mixed, although most positive effects are not sustained beyond the intervention period or immediately after it.⁴⁹ For cognitive modalities, evidence supports immediate reductions in pain intensity; however, similar to the finding for massage, evidence to support sustained reductions in pain are lacking.^{53,54}

For the pharmacologic management of mild to moderate pain, nonopioid analgesics, such as acetaminophen and nonsteroidal anti-inflammatory drugs, remain widely used in clinical practice. Opioids for mild to moderate pain are added at step two of the WHO analgesic ladder. Codeine phosphate and/or tramadol are commonly used, although this is supported by limited evidence. Two recent Cochrane reviews found only weak evidence to support their use,^{55,56} and some authors have suggested bypassing step two of the WHO analgesic ladder and proceeding directly

from step one to step three.^{57,58} Opioids, specifically morphine, remain the first-choice analgesic for moderate to severe cancer-related pain. A 2017 review of nine systematic reviews, (incorporating 152 individual studies) examining any opioid for cancer-related pain found that, on average, 19 of 20 patients with cancer with moderate or severe pain who receive opioids and can tolerate them will have their pain reduced to mild or no pain within 14 days.⁵⁹ Opioids should be given orally where possible and titrated individually to the lowest effective, tolerable dose.⁵⁸ Either immediate- or modified-release preparations can be prescribed regularly, with immediate-release preparations also available as required for breakthrough pain.⁶⁰ No evidence of superiority across opioids for moderate to severe pain exists: morphine remains the first-line opioid of choice in international guidance because of its familiarity, availability, and cost.⁵⁸ Fentanyl and buprenorphine are recommended in renal impairment (estimated glomerular filtration rate < 30)⁵⁸ when morphine is contraindicated.⁶¹ Despite limited evidence, switching between opioid preparations is common practice when the first-line opioid chosen is ineffective or poorly tolerated.⁶² Adverse effects from opioid therapy are common and predictable.⁵⁹ Constipation, nausea, and vomiting are most commonly reported, and guidelines recommend the use of laxatives with all opioid prescriptions.⁵⁸

More than 20% of patients with cancer experience neuropathic pain.⁶³ Although anticonvulsant or antidepressant medications are considered standard treatment of nonmalignant neuropathic pain, evidence for their effectiveness in cancer is mixed. A meta-analysis of four randomized controlled trials (RCTs) found no analgesic benefit from adding

pregabalin or gabapentin to opioids in patients with cancer-related pain.⁶⁴ By comparison, Jongen et al⁶⁵ found antidepressants and anticonvulsants effective and well tolerated in patients with confirmed cancer-related neuropathic pain, and in a separate double-blind crossover RCT, an opioid-sparing effect was found with the addition of pregabalin to opioid therapy.⁶⁶ As such, neuropathic pain agents remain recommended in international pain guidelines and should be considered an appropriate adjunct to opioids for patients with neuropathic pain.⁵⁸ Ketamine has not been shown to be effective for patients with cancer-related neuropathic pain, although it may have a role in a specific subsection of patients with hyperalgesia.^{67,68} A Cochrane systematic review found a lack of evidence to support the use of methadone as an adjuvant for cancer-related neuropathic pain.⁶⁹ Limited data suggest that it may have a role in patients with cancer-related pain unresponsive to morphine or other opioids.⁷⁰ Its complex pharmacology necessitates use by specialist physicians.

There is mixed evidence to support bisphosphonates for cancer-related bone pain. One systematic review found that 22 of 28 RCTs did not identify any analgesic benefit.⁷¹ However, a meta-analysis of studies including only patients with multiple myeloma (n = 8) found a difference in amelioration of pain with use of bisphosphonates compared with placebo or no treatment (pooled risk ratio, 0.75; 95% CI, 0.60 to 0.95), although the overall quality of evidence was found to be low.⁷² By comparison, radiotherapy has been shown to be highly effective in the management of cancer-related bone pain. A meta-analysis found that almost a third of those treated with radiotherapy experienced total resolution of pain at 4 weeks, with a single fraction of 8 Gy being effective.⁷³ Specialist pain interventions, for example,

nerve blocks, should be considered in patients with moderate to severe pain refractory to standard pharmacologic treatments.⁵⁸

Breathlessness

Breathlessness is a common symptom that becomes increasingly prevalent as disease progresses.^{74,75} Refractory breathlessness (that which persists despite optimal treatment of the underlying condition) is associated with a shortened life expectancy,^{76,77} can be especially frightening for patients and families,^{78,79} and often results in use of acute hospital services.⁸⁰⁻⁸³ Despite increased understanding of the mechanisms of breathlessness, new and effective treatment options remain elusive.⁸⁴ Thus, clinicians also experience distress when faced with refractory breathlessness because of the limited availability of effective interventions.^{6,78,79}

Management should start with optimizing the treatment of any underlying causes of breathlessness, especially bronchoconstriction.

Nonpharmacologic treatments should then be considered, in particular, positioning and breathing techniques, mobility aids, and muscle strengthening.⁸⁵ The importance and potential effectiveness of simple aids, such as a hand-held fan, should also not be overlooked.⁸⁶ For pharmacologic treatments, the European Respiratory Society and American Thoracic Society have both concluded that beyond oxygen and opioids, there is no robust evidence for other pharmacologic agents.^{84,87} Oxygen has a clear and accepted role for patients with hypoxia. However, in patients with mild or nonhypoxemic breathlessness, the benefit derived from oxygen is similar to medical air, and there are limitations to its use (eg, safety, cost).^{88,89} Relevant systematic reviews of effectiveness and

clinical trials are available for opioids, oxygen, and benzodiazepines.^{88,90-95} Although opioids by mouth and injection can reduce breathlessness, their effects are modest or small, and the optimal dosing, titration, and potential issues arising from long-term use (eg, safety, tolerance, dependence, misuse) remain to be determined.^{90,96} The evidence from Cochrane reviews does not support a role for benzodiazepines, except as second- or third-line treatment if opioids fail, because there is no overall evidence of benefit and some evidence of possible harms.⁹⁴

Holistic breathlessness services combine tailored nonpharmacologic and pharmacologic breathlessness management,⁹⁷ typically with input from multiple specialties and professions (eg, medicine, nursing, physiotherapy).⁹⁸ Such services represent an evidence-based means for early integration of palliative care on the basis of need rather than prognosis.⁹⁹ They are highly valued by patients and their carers and overall can lead to significant improvements in distress due to breathlessness and aspects of psychological health, including depression.⁹⁷ In a single-blind randomized trial, Higginson et al⁹⁸ assessed the effectiveness of a new breathlessness support service compared with usual care for patients with advanced disease and refractory breathlessness. The service comprised an initial outpatient clinic appointment with respiratory medicine and palliative care clinicians during which time patients were also provided with a breathlessness pack that included information, management, and pacing guidance, a hand-held fan or water spray, a poem (a short mantra to help breathing and relaxation during crises), and an individualized crisis management plan. Approximately 2 to 3 weeks later, patients received a home visit by a physiotherapist and/or occupational therapist to assess

their need for aids and adaptations, as well as to reinforce self-management of breathlessness and provide additional guidance on pacing and exercises. A second and final outpatient appointment with a palliative care specialist followed and allowed any additional actions to be incorporated and a discharge plan to be developed.⁹⁸ The study found significant improvements in breathlessness mastery in the breathlessness support service group compared with the control group (mean difference, 0.58; 95% CI, 0.01 to 1.15), as well as improvements in overall survival for patients with chronic obstructive pulmonary disease and interstitial lung disease but not cancer.⁹⁸

Nausea and Vomiting

Nausea, defined as the unpleasant subjective feeling of wanting to vomit or retch, and/or vomiting,¹⁰⁰ are experienced by as many as 68% of patients with cancer at some point during their illness; during the last 6 weeks of life, the prevalence of nausea and vomiting is 40% or more.¹⁰¹ Poorly controlled nausea and vomiting is associated with physical, cognitive, and psychosocial distress, and can contribute to patient and family fears of death from dehydration and/or starvation.^{102,103}

Nausea and vomiting secondary to antineoplastic agents or radiation therapy should be anticipated and managed according to ASCO antiemetic, or equivalent, clinical practice guidelines.¹⁰⁴ The latest ASCO antiemetic update includes evidence-based recommendations and information on the appropriate use of olanzapine, neurokinin 1 receptor antagonists, and use of subcutaneous 5-hydroxytryptamine-3 receptor antagonists.¹⁰⁴

Much less trial evidence is available for the use of antiemetics in patients with advanced cancer and nausea and vomiting unrelated to antineoplastic agents or radiation therapy.^{105,106} Instead, an etiologic or mechanism-based approach to choosing an antiemetic is commonly recommended.¹⁰⁷ This approach requires clinicians to take a detailed history and perform a focused examination to determine the most likely underlying cause(s) of the patient's nausea and vomiting. In the advanced cancer population, the most common underlying causes of nausea and vomiting are chemical abnormalities (eg, renal or liver failure, hyponatremia, hypercalcemia); drugs (eg, opioids, antidepressants, antibiotics); infection; and impaired gastric emptying, as well as visceral and serosal causes of delayed gastrointestinal transit (bowel obstruction, gastric bleed, enteritis, constipation).¹⁰⁸⁻¹¹¹ Once the most likely underlying cause of the patient's nausea and vomiting is determined, an appropriate antiemetic can then be selected based on the pathophysiology and receptors implicated ([Table 1](#)).¹⁰⁸

TABLE 1.

Etiology-Based Guidance for Antiemetic Prescribing

TABLE 1. Etiology-Based Guidance for Antiemetic Prescribing

Nausea and Vomiting Etiology	Mechanism and Receptors Implicated	First-Line Drug Options
Antineoplastic agents or radiation therapy	See specific ASCO guidance: https://www.asco.org/practice-guidelines/quality-guidelines/guidelines-for-supportive-care-and-treatment-related-issues	
Nausea and vomiting unrelated to antineoplastic agents or radiation therapy		
Chemical/metabolic	Stimulation of CTZ (D ₂)	Haloperidol
Drugs (not antineoplastic, eg, opioids)	Stimulation of CTZ (D ₂)	Haloperidol
	Delayed gastrointestinal transit from some medications may also contribute to nausea and vomiting, eg, secondary to opioids	Metoclopramide
Impaired gastric emptying/gastric stasis	Gastroparesis (D ₂)	Metoclopramide
Visceral/serosal causes of delayed gastrointestinal transit	Malignant bowel obstruction (stimulation of CTZ [D ₂]) and/or stimulation of peripheral pathways (muscarinic acetylcholine receptor, H ₁)	Cyclizine
Cranial causes	Activation of meningeal mechanoreceptors secondary to meningeal irritation with or without increased ICP	Cyclizine (with or without dexamethasone for increased ICP)
Vestibular causes	Stimulation via vestibulocochlear nerve (muscarinic acetylcholine receptor, H ₁)	Cyclizine

NOTE. Treat reversible/underlying causes of nausea and vomiting where appropriate/possible. Prescribe most appropriate first-line agent (on the basis of likely etiology) regularly and as needed; review at least every 24 hours. Consider parenteral administration if oral administration is in doubt.

Abbreviations: CTZ, chemoreceptor trigger zone; D₂, dopamine type 2; H₁, histamine type 1; ICP, intracranial pressure.

Unless contraindicated, antiemetics should be prescribed regularly and with a low threshold for being administered parenterally. If, despite titration, treatment with a single agent remains ineffective, a second-line antiemetic should be commenced. The addition of a second-line antiemetic is preferred over switching, because cancer-related nausea and vomiting is often multifactorial, involving multiple neurotransmitters and receptor sites.

Currently, only limited and low-quality evidence exists for the use of corticosteroids,¹¹² olanzapine,¹¹³ and cannabinoids^{114,115} for nausea and vomiting that is not secondary to antineoplastic agents or radiation therapy. Nonpharmacologic measures, such as dietary advice,¹¹⁶ psychological services,¹¹⁷ and acupuncture/acupressure,¹¹⁸ may offer some benefit when used alongside standard pharmacologic approaches, although again, evidence of their effectiveness for nausea and vomiting unrelated to antineoplastic treatment is limited.

Fatigue

Fatigue is “a subjective, unpleasant symptom which incorporates total body feelings ranging from tiredness to exhaustion creating an unrelenting overall condition which interferes with individuals’ ability to function to their normal capacity.”^{119(p527)} The severe and unrelenting nature of fatigue negatively affects patients and those close to them.^{120,121} It is highly prevalent, affecting three quarters of patients with advanced cancer, perhaps related to the proinflammatory state that plays a role in its pathogenesis.¹²² Other contributing factors include anemia, malnutrition, neuro-endocrine impairment, and muscle dysfunction.¹²³ Assessment of fatigue can be via single-item tools (eg, 0 to 10 numeric rating scale), unidimensional (eg, Functional Assessment of Cancer Therapy: Fatigue), or multidimensional (eg, European Organisation for Research and Treatment of Cancer QLQ-FA13 and Chalder Fatigue Scale) scales (for a comprehensive review, see Minton and Stone¹²⁴).

Both nonpharmacologic and pharmacologic treatments for fatigue are available. These should be considered once treatment of any

underlying/reversible causes of fatigue have been optimized. Proactive monitoring and protocolized management of physical symptoms can improve general fatigue, as well as affect activity levels and motivation.¹²⁵ The use of exercise for fatigue is supported both during and after anticancer treatment (standardized mean difference [SMD], -0.27; 95% CI, -0.37 to -0.17),¹²⁶ with consistent secondary effects on depression and sleep quality,¹²⁷ although most studies are limited to patients with primary breast cancer receiving adjuvant chemotherapy or patients with prostate cancer. The strongest evidence is for aerobic exercise (eg, walking, cycling). Resistance training may have an additional role in cancers where cachexia is highly prevalent, for example, lung and pancreatic, although studies for these groups are fewer in number and smaller.¹²⁶

Evidence is relatively weaker and less consistent for other nonpharmacologic treatments, although arguably more applicable, being limited to those with advanced, incurable disease. There is restricted support for psychosocial interventions, including cognitive behavioral or expressive group therapies (SMD, -0.25; -0.50 to 0.00),¹²⁸ although benefit has been found after cancer treatment.¹²⁹ Educational interventions involving information giving with reinforcement or problem-solving led to small improvements in fatigue intensity (SMD, -0.28; 95% CI, -0.52 to -0.04), general fatigue, distress related to fatigue, and interference with daily life.¹³⁰ Music interventions also led to a small-to-moderate effect (SMD, -0.38; 95% CI, -0.72 to -0.04), although some studies feature a high risk of bias, including inadequate randomization, and the anxiety-relieving effect is stronger.¹³¹ There is insufficient evidence for

complementary and alternative medicines, including acupuncture and hypnosis.^{132,133}

Once nonpharmacologic treatments have been used, the psychostimulant methylphenidate can be considered.^{134,135} In 2011, a meta-analysis of five psychostimulant trials, four of which related to methylphenidate, found an overall SMD for psychostimulant use of -0.28 (95% CI, -0.48 to -0.09).¹³⁶ However, more recent and larger RCTs have found methylphenidate to be ineffective for the management of cancer-related fatigue, with evidence of benefit limited to patients with narcotic-induced fatigue and/or depression.¹³⁷⁻¹⁴² Evidence for modafinil is mixed, with two trials concluding either no benefit¹⁴³ or benefit only with severe fatigue.¹⁴⁴ For patients with anemia, including during chemotherapy, the hemopoietic growth factor erythropoietin reduces fatigue (SMD, -0.36 ; 95% CI, -0.46 to -0.26), whereas evidence for darbepoetin is less consistent.¹⁴⁵ Single trials support short-term use of dexamethasone, although efficacy and safety beyond 2 weeks are undetermined.¹⁴⁶ There is currently no evidence of benefit from L-carnitine supplementation,¹⁴⁷ progestational steroids, or paroxetine.¹⁴⁵

In summary, most patients with advanced cancer experience symptoms throughout the disease trajectory, often with greater intensity as death approaches. If poorly managed, such symptoms can have a considerable impact on patients' ability to function, quality of life, ability to comply with anticancer treatments, and use of health care resources. All clinicians involved in the care of patients with cancer should be competent in symptom assessment and management. For complex, multiple, and/or refractory symptoms, patients may benefit from additional support services,

such as those provided by specialist palliative care. Multidisciplinary palliative care teams have been shown to improve patient outcomes,¹⁴⁸⁻¹⁵⁰ and current ASCO guidelines therefore recommend that patients with advanced cancer should receive dedicated palliative care services, early in the disease course, and concurrent with active treatment.¹⁵¹ At a service level, managers and policymakers should consider incorporating routine screening of symptoms into usual care structures, with evidence that symptom assessment tools can improve patient outcomes and possibly even survival.

Old age and palliative care

Old age and palliative care go hand-in-hand. World Health Organization and Worldwide Palliative Care Alliance estimate suggest that among adults in need of palliative care, 66% to 69% are elderly over 60 years of age.

Among conditions requiring palliative care¹ Alzheimer's, Parkinson's, chronic respiratory diseases, cardiovascular diseases, diabetes, rheumatoid arthritis and cancer are common amongst the elderly. Old age related weakness in absence of any other medically diagnosed condition though not listed anywhere in the literature available as requiring palliative care will constitute a major proportion of the need of palliative care services in India. In a study done in urban areas of Puducherry to estimate the need of palliative care in the general population, it was found that 9 out of 22 people (44%) in need of palliative care were suffering from only old age related weakness. 2

The assessment was based on three questions. First, is there anyone in your family who is bedridden? Second, is there anyone in your family who is unable to go to work because of a physical illness? And third, is there anyone in your family who is not well and needs help to look after his/her activity of daily living? On an average, at 60 years of age, people in India are expected to live for another 18 years.³

So, whether or not, elderly are suffering from any of the conditions requiring palliative care, they will be in need of palliative care services as they are living longer with frailty and problems, which are psychosocial and also spiritual. But in the health programme for the elderly, NPHCE (National Programme for Health Care of the Elderly), which was launched in 2010-11, there is no mention of palliative care.⁴

Elderly in rural areas

With the demographic transition in India, the number of elderly is increasing. The projected proportion of elderly in the total population will be 11.1% in 2025 (United Nations Department of Economic and Social Affairs [UNDESA], 2008), up from 7.5% in 2010. In terms of absolute numbers, elderly population in India is projected to reach 158.7 million by 2025 (United Nations Department of Economic and Social Affairs, 2008).⁵ Most elderly in India will be in rural areas as the trend suggests. As per the 2011 census and SRS 2013 data, 68.8% of the total population is in rural areas, whereas for elderly, 70.5% reside in rural areas. The situation is worse in rural areas with higher proportion of elderly living with disabilities, mostly locomotor and visual and higher dependency ratio as compared to urban areas (15.1 vs 12.4).³ Care for

such elderly is becoming difficult because of increasing trend towards nuclear families and also migration of younger population to urban areas leaving the elderly behind in villages with fewer caregivers. Poverty is also more in rural areas increasing the burden of psychosocial care for the elderly. The implications of this being that elderly in need of palliative care in rural areas are either uncared for or minimally cared with immense strain on the caregivers. Palliative care, which focuses not only on the patients, but also the caregivers and family members has become necessary in the present situation.

Health services for elderly in rural areas

All the health programmes are presently being implemented through the sub-centres manned by MPHWM (Multi-Purpose Health Worker - Male) and MPHWF (Multi-Purpose Health Worker - Female) catering to a population of 5000 in plains and 3000 in difficult terrains.⁶ This being equivalent to five to six villages, which in some states and less densely populated areas is scattered over wide geographic areas.

The number of MPHWM is very low in all states of India. Number of MPHWF is also lower than the requirement as per the norms.⁶ Primary responsibility of the MPHWF is maternal and child health. She is also expected to do multiple activities under various other national health programmes like NPCDCS, NMHP and so on.

It sounds logical to add the responsibilities as mentioned in NPHCE under the sub-centre level - Domiciliary visits for attention and care to home bound / bedridden elderly persons and provide training to the family care providers in looking after the disabled elderly persons. But given that the services under the

RMNCH+A (Reproductive, Maternal, Newborn, Child and Adolescent Health Programme) are quite demanding especially with concentrated efforts in reducing maternal and neonatal deaths, the MPHW-F is overburdened.

Considering a more pragmatic approach, in the given scenario, the expectation of the NPHCE to cater to the geriatric age group through the MPHW-F in the rural areas is utopian.

Elderly will continue to remain a neglected group. The principles of palliative care need to be incorporated into the NPHCE and focus should shift from providing services through the health care system to community based palliative care coordinated and supported by the health care system. Lessons learnt from Kerala in developing a successful model of community involvement in providing palliative care to the needy are still not infused into the rest of the country.

But if we want a better quality of life for the elderly and more comfortable death for the fast aging population of our country, we need to consider palliative care for the large number of elderly in the rural areas of India. Greater collaborations with community based organizations and Non-governmental organization will have to be in place to spread the message of palliative care in the villages, encourage volunteer centered community based palliative care programmes, which should be supervised by the health system through the Primary Health Centres (PHC) and Sub-centres.

The Medical Officers of PHC and MPHW-M and MPHW-F at sub-centres need to be trained in palliative care to be able to do this. A more inclusive programme is required for sustainability of the palliative care services for the old

and suffering population of this vast country through collaborations at various levels and various organisations for capacity building, provision of services, supervision and monitoring

Introduction

Although this session was originally entitled "Psychosocial Assessment and Management," the three presentations reflected the fact that effective psychosocial assessment and management, and the auditing of care, must all be seen as integral components of the total care of the patient and family.

It has been shown that physical symptoms in the person in the terminal phase of disease are associated with increased distress, as well as major depression and anxiety. Severe pain, which was inadequately controlled and poorly tolerated, has been associated with suicide in cancer patients. In addition, the burden of illness is borne by family members who may also experience distress and poor health] financial problems, and disruption of their work lives. It is only recently that any attempt has been made to audit the care of the terminally ill and to recognize the importance of auditing family response to terminal illness.

The Patient's Experience with Terminal Cancer

The symptoms of persons in the terminal phase of illness living in the community have been documented in a number of studies from different countries. In the first part of this session, Vachon reported on a Canadian study of 69 terminally ill patients who constituted 5% of a

community, sample of 1319 persons living with cancer interviewed in the Needs Assessment of Persons Living with Cancer in Three Canadian Provinces. 19-21 The symptoms reported by this group were contrasted with preliminary data from 23 terminally ill inpatients studied by Vachon and Fitch 22 as a part of a study of 100 inpatients and 400 outpatients, using the instruments developed in the larger study and the 30-item Goldberg General Health Questionnaire (GHQ) .23 Table 1 shows a comparison of the above studies with symptoms reported by terminally ill patients in two other studies. Addington-Hall and colleagues¹⁴ reported on data obtained from 203 terminally ill patients who were seen at least twice as part of a study to measure the impact of a nurse coordinator on the care of terminally ill patients living at home. Coyle and colleagues¹⁵ presented data on the symptoms during the last month of life reported by patients referred to the Supportive Care Service of Memorial Sloan-Kettering Cancer Center because of clinically challenging physical problems, poorly controlled symptoms, and psychologic or social dysfunction. In that study, it was noted that the symptoms reported were limited to those mentioned by patients, as opposed to an assessment of particular symptoms. The authors note that symptoms may, therefore, be underreported. It can be seen that pain was a major symptom for 55%-100% of subjects. 14,18-22 Although not 144 Vachon et al. Vol. 10 No. 2 February 1995 all studies assessed the same symptoms, it can be seen that major symptoms in these terminally ill samples, most of whom were living at home, included decreased energy/weakness (43%- 94%); 18-22 tiredness/fatigue (58%-71%); 18-22 appetite disturbances (47%-67%); 14,19-22 psychological distress including self-reported anxiety (21%-43%), 14A8 self-reported depression (50%-56%), 14 suicidal ideation (20% plus 4% with suicidal

intent),is and self-reported feelings of depression, anxiety, and frustration (29%- 71%). 19-22 In addition, terminally ill patients reported breathing problems (17%- 61%); 14,18-22 nausea (12%-49%); 14,18-22 decreased ability to walk or climb stairs (18%- 74%); 18-22 sleep problems (24%- 54%); 14,18-22 constipation (30%-42%), 14,19-22 and difficulty concentrating/confusion (24%-43%). 14,19-z2 Clearly, the major symptoms reported in these four studies were similar, although the frequency of symptoms varied fairly widely. The differences presumably reflect both diagnostic differences as well as the efficacy of treatment. Future studies are needed to compare the symptoms of similar samples of those terminally ill who are receiving palliative treatment in a variety of settings and to measure the effectiveness of the intervention strategies used.

Psychological Distress Associated with Terminal Illness

In the Canadian studies, 19-2'2 physical symptoms were associated with high distress on the 30-item GHQ: 61%-79% of the terminally ill outpatient sample, compared with 18%-34% of the total sample, had high distress as measured on the GHQ. Of those who reported pain in the past week, 90%-100% had high distress. In the preliminary analysis of the hospital study, 22 83% of terminally ill inpatients had high distress on the GHQ. 2`~

Practical Service Needs Associated with Terminal Illness

The Needs Study assessed both the met and unmet need for a variety of services, including practical services. In the Quebec sample, 21 the terminally ill group used agency nursing care (54%), agency housework (29%), agency transportation to and from medical appointments (21%), and

financial assistance from family and friends (17%). Unmet needs for practical services included housework (29%), nursing care (17%), financial assistance during treatment (17%), and a place for the family to stay while one was having treatment (8%). Houts and colleagues I retrospectively studied the needs of 433 terminally ill cancer patients during their last month of life. They estimated that 72% of persons who died of cancer in Pennsylvania during that time period experienced at least one unmet service need during the last month of life. The most frequently reported needs were for help with activities of daily living (42%); emotional and physical unmet needs (21%); problems with medical staff (20%); insurance needs (19%); and financial unmet needs (15%). Mot, Guadagnoli, and Wool 24 reviewed 12 studies of the unmet needs for concrete services of cancer patients and found that, not surprisingly, cancer patients' needs increased with the severity or duration of illness. This need was apparent for both the personal care (activities such as bathing and dressing) and instrumental activities (shopping, cooking, and cleaning). This finding seemed to be more associated with the rate of disease progression than with the specific type of disease. Older patients, nonwhites, and those with economic problems were found to have greater needs. Analyzing data from 413 patients undergoing chemotherapy, 63% of whom were receiving palliative care, Mor and colleagues found that 88% reported at least one need in the instrumental area that was unmet in 19%. Unmet need was generally greater for palliative patients, particularly those with breast cancer. For both groups, need and unmet need were greatest for heavy housework. Future studies are needed to ascertain which practical needs can realistically be met and whether such interventions have an impact on the patient's ability to spend more of the terminal period at home.

Family Satisfaction with Advanced Cancer Care

Kristjanson presented an overview of research related to families and cancer, which was based on a literature review summarizing approximately 200 articles in *Cancer Nursing* written between 1970 and 1991.²⁵ Four major dimensions of the family cancer experience were identified from the literature: development- Vol. 10 No. 2 February 1995 *Psychosocial Issues in Palliative Care* 145 mental stage of the family, cancer illness trajectory, family responses to cancer, and health-care provider behaviors important to family care.

Developmental Stage of the Family

Research revealed that families experience different concerns, problems, and developmental issues depending on their developmental stage. Although research across different family developmental stages is identifiable, the research is, for the most part, not based on explicit theoretical frameworks that clearly articulate the developmental stage of the family. More work is needed to systematically examine the relationship between normal developmental milestones of families as they encounter the cancer illness experience.

Cancer Illness Trajectory

Analysis of literature revealed that families experience stresses and have different needs at various stages of the illness trajectory. Very little research has been undertaken to understand the family during the preventive stage of cancer, despite the fact that certain familial factors may be predictive of some cancers (for example, breast cancer).²⁶⁻²⁸ Research addressing both the information and support needs of families

during this phase are notably absent. There is strong evidence that family members experience considerable stress when a member is diagnosed with cancer and may have higher levels of anxiety than patients themselves. 29-31 Only a handful of researchers have investigated the family cancer experience in the recurrent phase of the illness, documenting the fear, anger, and uncertainty that family members feel during this time. 32,33 To date, no research has been undertaken to test different models of family rehabilitation. There is a growing body of literature documenting the family's experience during later phases of the illness. Concerns of families during this stage center around worries about the patient's comfort, emotional intensity of losing the patient, and need for information. Families may be willing to play a more active role in care decisions at this stage. Grief reactions of families may be influenced by factors such as the type of death and location of death. 34-36 Intervention studies to assist families at all stages of the trajectory are needed. Family Responses to Cancer Family responses included literature related to the family's needs, demands on the family, role changes, communication changes within the family, coping strategies, and family health changes. The family's need to know that the patient is comfortable and to receive information about the illness is repeatedly documented in the literature. 37-44 Families experience a number of demands, such as practical tasks of daily living and providing physical care to the patient. 45,46 Communication within the family may also change in response to the cancer illness, 47 with families often exhibiting less open communication to protect the patient from discussions of "negative topics" (for example, illness, symptoms, and impending death). There is need for further research to identify ways of assisting families to communicate about the illness in ways that are helpful in coping with the

disease. Family members may use different coping strategies depending on prior coping techniques and their position in the family. External resources may be helpful in meeting practical and emotional needs of families. 44,48 However, the concept of social support for different families at various stages of the illness trajectory is poorly understood. Responses to the cancer illness have also been described in terms of physical and psychological health changes of family members, 29'49 both during the illness and in the bereavement period.

Health-Care Provider Behaviors Important to Family Care

A fourth category of literature reviewed included studies related to health-care provider behaviors important to family care. This research revealed the importance of caregiver behaviors aimed at providing high-quality physical care to the cancer patient. Needs for information are secondarily ranked as a priority by family members. Families report difficulties obtaining information from health professionals, and report a lack of supportive care and counseling. There is evidence that hospice services may provide specific benefits to families. 5°-5:~ Research directed at care approaches for families during the palliative-care phases of the illness trajectory are needed. 146 Vachon et al. Vol. 10 No. 2 February 1995 Kristjanson presented research performed in this category during the last 10 years that involves a number of phased projects, all with the overall goal of improving the quality of care provided to families of patients with advanced cancer. Phase I of the research program was a qualitative study to identify health-care behaviors important to families of advanced cancer

patients. Thirty-three family members of terminally ill cancer patients participated in in-depth interviews, which were transcribed and analyzed. Two major categories of health-care behaviors were identified: 74 behaviors important to patient care and 77 behaviors important to family care. 42 Phase II of the research used these items as the basis for administration of a Q-sort to 210 family members from three different care settings. This phase resulted in the identification of the most-salient indicators of quality of cancer care from a family perspective. 4:~ Phase III was an instrument development and testing phase. The most salient items from Phase II were used to develop the FAMCARF Scale (20 items) to measure family satisfaction with advanced cancer care. 54 Phase IV was designed to test four theories of satisfaction using theoretical and empirical modeling. Of the four theories, discrepancy theory was the most credible, accounting for 68% of the explained variance in family-care satisfaction. Empirical modeling resulted in identification of the Family Care Satisfaction Model, explaining 78% of the variance in care satisfaction. 55 Currently, a study is underway that extends the theory-testing project by including additional variables that might serve as meaningful covariates (for example, symptom distress of patient), and testing the extent to which family-care satisfaction, as measured in the end stages of the care experience, is a predictor of health status of family members and family functioning in the bereavement period. 56

Auditing Psychosocial Care

Defining Audit

Clinical audit is the systematic critical analysis of the quality of clinical care, including the procedures used for diagnosis and treatment, the use of resources and the resulting outcome and quality of life for the patient. 57 Audit cannot determine whether a therapy or intervention is better than no therapy or an alternative intervention--such a question would usually require a randomized controlled trial.

An audit can, however, examine the treatment and problems of most patients receiving care, rather than just those selected and included in a clinical trial. It can also identify failings as well as successes in practice. Perhaps the most important feature of audit is the requirement for feedback of the results to all staff and then to seek, apply, and monitor ways to improve care. Thus, the audit cycle is repeated.

Auditing Care

To systematically assess patient and family problems, valid, reliable, appropriate, responsive, quick, and user-friendly measures are needed. Although the validity and reliability of measures are often studied, responsiveness is rarely reported. Clinicians need to decide what is the smallest clinical change that the measure should detect. If measures become too lengthy, however, then they are time consuming and not practical for routine or audit use. Thus, short measures have considerable advantages.

Measures can assess the structure (the resources), the process (the use of resources), or the outcome (the result) of care. Examples of process aspects are the use of drugs, the number of patient visits, and the procedures followed. Examples of outcome aspects are symptom control,

relief of anxiety, quality of life, and satisfaction. Outcome is the most important for the patient and family, but this is also the most difficult to measure. Although many of the research instruments used to assess quality of life could be used to audit care, these are often too lengthy or complex for routine use.

Measures that have been used to audit care include the Support Team Assessment Schedule (STAS), 5s which includes 17 items: 10 assessing the patient and family and 7 assessing the services. The measure has been validated for use in very sick patients, was demonstrated to be responsive to change, and is reliable. The median time to complete a STAS assessment (following a normal palliative assessment) is 2 min. The Edmonton Symptom Assessment Scale 16 can also be used to audit care. This records nine items, which are completed by patients using visual analogue scales. Early results from the Vol. 10 No. 2 February 1995 Psychosocial Issues in Palliative Care 14 7 validation appear very promising. A number of other measures are developed and are currently being tested, such as the Palliative Care Core Standards 59 and topic audit, by Finlay, 6° that has looked at single aspects of care such as communication with family doctors.

However, although the audit of pain and symptoms is reasonably well developed, the audit of psychosocial aspects--although present in the audits above--are less well refined. Much more work on the development and use of simple tools to audit psychosocial aspects of care is needed.

Results from audits have usefully identified failings in care, such as difficulties in assessing spiritual needs or inadequate alleviation of family

anxiety and dyspnea. Audits have also demonstrated successes in controlling pain, helping patient anxiety and communication. Audit results can also be used to develop clinical algorithms to help identify those patients most at risk of future problems.

General Recommendations

After listening to the presentations and the ensuing discussions, the group consensus was that there is a need for more effective tools to measure both symptoms and the burden of illness over an extended period of time; and that these tools must be brief; easily completed by patients, family members, or staff; sensitive to change over time; valid and reliable.

The following studies were recommended:

1. It was recommended that there be a workshop convened to further the development of instruments to be used in palliative care to assess such areas as • Delirium or other cognitive impairments (for example, dementia) • Mood • Family coping and family distress • Patient distress (including issues associated with distress, fantasies, and fears) • Patient coping • Spiritual needs The goal would be to better detect and/or screen patients and families at risk in order to appropriately intervene. Through repeated measurements, closer monitoring of patients and their families would have direct benefits on their care. It would also allow researchers to better understand and describe this last stage of disease for patients and families, including the bereavement period. Instrumentation must meet scientific and clinical criteria. However, measurement tools do not constitute an end in themselves, but rather the means by which patient care can be enhanced and research questions explored.

2. Given the interaction between the physical symptoms of the patient and both patient and family distress, it is recommended that there be studies to determine whether interventions to decrease the physical symptoms of patients lead to changes in patient/family psychosocial adaptation and distress and whether psychosocial/spiritual interventions will impact on symptoms, patient/family quality of life, psychosocial adaptation, and distress alleviation • During illness • In the bereavement period One of the goals of this study would be to determine which specific palliative-care interventions work best in which types of problems of patients and families.

3. Given that palliative care is occurring in many different settings, it is recommended that there be studies to examine the appropriate and optimal delivery of palliative care in order to operationalize the process and expected outcomes of palliative care and to describe the epidemiology of palliative care problems. These studies would address the issues of defining palliative care, its outcomes, and how to measure them (that is, operationalize "good palliative care"). Using standardized tools these studies would assess • The outcome of palliative care for the patient and family in different settings including patient/family satisfaction with care -- During the terminal phase --In bereavement The role and impact of patient/family decision making with regard to choosing the place of death Demographic variables, including socioeconomic factors and culture The service delivery process including communication and collaboration with other agencies and how this influences palliative care 148 Vachon et al. Vol. 10 No. 2 February 1995 • Cost analysis of various service-delivery models

4. Given the need for accountability in these days of severe economic constraints, it is recommended that there be studies to determine the impact of audit and quality improvement models of palliative care. Such audits would provide direct feedback to those involved. The goal would be to improve the quality of palliative care through influencing patterns of practice.

5. Given that there is as yet no clear taxonomy in the field of palliative care, it is recommended that effort be directed toward developing a palliative care taxonomy.

6. It is recommended that there be a study to develop family typologies of adaptation to terminal illness to

- Identify high-risk groups [including such variables as number of family members, socioeconomic structure, developmental level, previous social structure, and different family forms and family types (for example, step-families)]
- Develop and test methods of intervention looking at outcome variables such as --

Patient/family/staff communication breakdown --Family anxiety --Spirituality --Family satisfaction across the illness trajectory --Physiological measures - -Bereavement outcomes

7. Although common wisdom indicates that it is helpful to build in support systems for staff in palliative care, it is recommended that there be a study to measure whether staffsupport programs

- Impact on patient care
- Influence empathy of staff
- Improve patient/family/staff communication

INTRODUCTION

While dying is a normal part of life, death is often treated as an illness. As a consequence, many people die in hospitals, alone and in pain.¹ Palliative care focuses primarily on anticipating, preventing, diagnosing, and treating symptoms experienced by patients with a serious or life-threatening illness and helping patients and their families make medically important decisions. The ultimate goal of palliative care is to improve quality of life for both the patient and the family, regardless of diagnosis. Although palliative care, unlike hospice care, does not depend on prognosis, as the end of life approaches, the role of palliative care intensifies and focuses on aggressive symptom management and psychosocial support.

Helping patients and their families understand the nature of illness and prognosis is a crucial aspect of palliative care near the end of life. Additionally, palliative care specialists help patients and their families to determine appropriate medical care and to align the patient's care goals with those of the healthcare team. Finally, establishing the need for a medical proxy, advance directives, and resuscitation status is an integral part of palliative care at the end of life.

MODELS OF CARE

The traditional medical treatment model has become dichotomous, leading physicians to provide curative or aggressive treatment initially and to initiate comfort care only when other measures have failed. Palliative medicine establishes goals to relieve suffering in all stages of disease and is not limited to comfort care or end-of-life care ([Figure 2](#)).³



Models of healthcare delivery. (Reproduced with permission from the National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care. 2008.)²

The terms palliative care and hospice care are sometimes used interchangeably. According to the National Quality Forum, hospice care is a service delivery system that provides palliative care/medicine when life expectancy is 6 months or less and when curative or life-prolonging therapy is no longer indicated.⁴ Therefore, it is important to distinguish that although hospice

provides palliative care, palliative care is not hospice. Not all available therapeutic palliative care modalities are provided within the hospice service delivery system.:

THE CONCEPT OF TOTAL PAIN

The alleviation of suffering is an essential goal of medical care. To treat it, however, providers must first recognize pain and suffering.⁵ Saunders first described the concept of total pain (Table 1)⁶ and interaction among the various sources of pain and suffering.⁷ Total pain is the sum of the patient's physical, psychological, social, and spiritual pain. This concept is central to the assessment and diagnosis of pain and suffering.

Table 1.

Four Components of Total Pain

P	Physical problems, often multiple, must be specifically diagnosed and treated.
A	Anxiety , anger, and depression are critical components of pain that must be addressed by the physician in cooperation with other healthcare professionals.
I	Interpersonal problems, including loneliness, financial stress, and family tensions, are often interwoven into the fabric of a patient's symptoms.
N	Not accepting approaching death, a sense of hopelessness, and a desperate search for meaning can cause severe suffering that is unrelieved by medications.

Reproduced with permission from Bial A, Levine S. The assessment and treatment of physical pain associated with life-limiting illness. *Hospice/Palliative Care Training for Physicians: UNIPAC*. Vol 3. 3rd ed. Glenview, IL: American Academy of Hospice and Palliative Medicine; 2007.⁶

Because psychological distress, lack of social support, and physical pain are associated,⁸ treating a patient's total pain is imperative, especially at the end of life. Optimal pain relief will not be possible unless all the elements of total pain are addressed. Clinicians should utilize other members of the multidisciplinary team, such as social workers and chaplains, to better treat suffering related to the different domains of total pain.

MANAGING COMMON PHYSICAL SYMPTOMS

Patients near the end of life may experience extreme symptoms that include physical, spiritual, and psychosocial suffering. Preventing and managing these symptoms while optimizing the quality of life throughout the dying process is the goal of palliative medicine.⁹ Factors important to seriously ill patients include adequately controlling pain and other symptoms, avoiding prolongation of the dying process, achieving a sense of self-control, finding meaning in life, and relieving the care burdens of family and loved ones while strengthening and completing those same relationships.¹⁰ As death becomes nearer, the symptom burden increases while the patient and family tolerance of physical and emotional stress decreases. At this time, primary palliative care interventions should take precedence, and the focus on restorative care should decrease. The triggers for the shift to palliative care include the following four symptoms.

Physical Pain

Pain is one of the most prevalent symptoms near the end of life. Unrelieved pain can be a source of great distress for patients and families and exacerbate other symptoms. Therefore, the adequate management of pain at the end of life is imperative. Although opioid analgesics are the standard of care for treating moderate to severe pain in patients with advanced illness, the false fear that opioids induce respiratory depression and hasten death is a major barrier to their use at the end of life. However, both effects are uncommon when opioids are given at appropriate doses. Clinicians who care for the chronically ill and for those at the end of life should acquire competency in pain management.¹¹

Dyspnea

Dyspnea, the subjective sensation of breathlessness, is a frequent and distressing symptom, particularly in dying patients. Opioids and benzodiazepines are the most widely prescribed medications for treating dyspnea. As death approaches, a clinician may use continuous infusions to manage symptoms and relieve suffering if scheduled or as-needed doses are not adequate. The clinician should continually assess the patient and make adjustments that will control symptoms.¹²

Restlessness

Providers should recognize the signs and symptoms of the restlessness associated with delirium at the end of life ([Table 2](#)).¹³ The most common identifiable cause of delirium in the hospital setting is medication: anticholinergics, sedative-hypnotics (eg, benzodiazepines), and opioids. Delirium and restlessness at the end of life are usually characterized by anguish (spiritual, emotional, or physical), anxiety, agitation, and cognitive failure. The treatment of terminal delirium usually requires the use of a major tranquilizer such as haloperidol.¹⁴

Table 2.

Signs of End-of-Life Restlessness

The constellation of end-of-life restlessness symptoms may include the following:

- Skin mottling and cool extremities
- Mouth breathing with hyperextended neck
- Respiratory pattern changes such as Cheyne-Stokes
- Calling out for dead family members or friends
- Talking about packing bags, taking a trip, going for a car ride (any reference to preparing for a trip)
- Periods of deepening somnolence

Reproduced with permission from Policzer JS, Sobel J. Management of selected nonpain symptoms of life-limiting illness. *Hospice/Palliative Care Training for Physicians: UNIPAC*. Vol 4. 3rd ed. Glenview, IL: American Academy of Hospice and Palliative Medicine; 2007.¹³

Death Rattle

As responsiveness decreases toward the end of life, it becomes increasingly difficult for patients to control oropharyngeal secretions. The death rattle of the actively dying is the sound of air movement across pooled secretions. Although not a cause of suffering for the dying, the death rattle can be disturbing for loved ones to hear. Repositioning the patient's head and using anticholinergics such as atropine or scopolamine are the mainstays of treatment

PSYCHOSOCIAL, SPIRITUAL, AND BEREAVEMENT SUPPORT

Once the physical adverse symptoms and distress have been successfully addressed, it is important to broaden the integrated response of the interdisciplinary treatment team to address the psychosocial and spiritual issues that are an inherent part of the dying process. A comprehensive psychosocial and spiritual assessment allows the team to lay a foundation for healthy patient and family adjustment, coping, and support. Skilled expert therapeutic communication through facilitated discussions is beneficial to maintaining and enhancing relationships, finding meaning in the dying process, and achieving a sense of control while confronting and preparing for death ([Table 3](#)).¹⁶

Table 3.

Psychosocial and Spiritual Assessment of the Patient With a Life-Threatening Illness: Sample Screening Questions

Psychosocial Assessment Domain	Screening Questions
Meaning of illness	<i>"How have you made sense of why this is happening to you?"</i> <i>"What do you think is ahead?"</i>
Coping style	<i>"How have you coped with hard times in the past? What have been the major challenges you have confronted in your life?"</i>
Social support network	<i>"Who are the important people in your life now? On whom do you depend and in whom do you confide about your illness?"</i>
Stressors	<i>"How are the important people in your life coping with your illness?"</i> <i>"What are the biggest stressors you are dealing with now?"</i> <i>"Do you have concerns about pain or other kinds of physical suffering? About your and your family's emotional coping?"</i>
Spiritual resources	<i>"What role does faith or spirituality play in your life? What role has it taken in facing difficult times in the past? Now?"</i>
Psychiatric vulnerabilities	<i>"Have you experienced periods of significant depression, anxiety, drug or alcohol abuse, or other difficulties in coping?"</i>
Economic circumstances	<i>"What kinds of treatment have you had and which have you found helpful?"</i> <i>"How much of a concern are financial issues for you?"</i>
Patient-physician relationship	<i>"How do you want me, as your physician, to help you in this situation? How can we best work together?"</i>

Reproduced with permission from Block SD. *JAMA*. 2001 Jun 13;285(22):2898-2905.¹⁶

Compassionate palliative care requires a professional readiness of those specialized in this field to explore the integrity-preserving issues that will foster growth in dignity and transcendence. Reflective open-ended questions are key in optimizing this communication and assessing the willingness of the patient and caregivers to engage. Physicians, psychologists, nurses, social workers, and chaplains can assimilate and negotiate the interpersonal relationship skills and intimacy required to enhance the patient's peace and psychosocial spiritual comfort (Table 4).¹⁶

Table 4.

Useful Questions for Clinicians

A. Mobilizing a patient's coping strengths and inner resources

- *"What will help you feel that you have lived up to your own ideals in the way you've dealt with your illness/your death?"*
- *"What could you do that would help you feel that this has been a meaningful time for you and the people you care about?"*
- *"How do you want to be remembered by the people you care about?"*
- *"What are some of the ways you have found yourself growing or changing, or hoped that you could grow or change in this last phase of your life?"*
- *"What are some of the moments when you've felt most discouraged and downhearted as you've faced your illness?"*
- *"What are the biggest barriers you find to feeling secure and in reasonable control as you go through this experience with your illness?"*
- *"What are the resources and strengths within you that can help you cope?"*

B. Eliciting a patient's goals for healing and strengthening relationships

- *"Are there important relationships in your life, including relationships from the past, that need healing or strengthening?"*
- *"Are there relationships in which you feel something important has been left unsaid?"*
- *"Do the important people in your life know what they mean to you?"*
- *"Are there stories, values, or ideas that you want to transmit to people as part of your legacy?"*
- *"Are there ways that you can help your family now to prepare for and deal with your death?"*
- *"How might you be able to continue to be a presence in the lives of people you love after you are gone?"*
- *"How would you like to say goodbye to the people who have been important to you?"*

Reproduced with permission from Block SD. JAMA. 2001 Jun 13;285(22):2898-2905.¹⁶

THE "WORK" OF DYING

Many patients imagine that death comes suddenly, but for many, the knowledge that one's death is imminent comes first. Those with this awareness often must complete certain tasks to allow a peaceful death such as offering forgiveness, being forgiven, acknowledging regrets, finding closure in professional and community relationships, and saying goodbye to family and friends.

GUIDELINES

The National Cancer Comprehensive Network (NCCN) has published guidelines for the palliative care of cancer patients.¹⁷ Recommendations offered by NCCN cover many of the topics discussed in this article and are an excellent resource for the palliative care of patients with cancer and other life-threatening conditions.

CONCLUSION

The role of palliative care at the end of life is to relieve the suffering of patients and their families by the comprehensive assessment and treatment of physical, psychosocial, and spiritual symptoms patients experience. As death approaches, the symptom burden of a patient may worsen and require more aggressive palliation. As comfort measures intensify, so does the support provided to a dying patient's family. Once death has occurred, the role of palliative care focuses primarily on the support of the patient's family and bereavement.

VALUE ADDED COURSE

PALLIATIVE CARE

Annexure II

STUDENT ENROLLMENT LIST (JAN 2022)

S.No.	University no	Name of the student	Year / CRR1	Signature
1.	U15MB350	SAKTHI RENGARAJAN. S	II nd	
2.	U15MB351	SAKTHIYANATHAN .S	II nd	
3.	U15MB352	SANDIYA. T	II nd	
4.	U15MB353	SARANKUMAR. B	II nd	
5.	U15MB354	SARANYA R.E	II nd	
6.	U15MB355	SARANYA. E	II nd	
7.	U15MB356	SARATH KUMAR. A	II nd	
8.	U15MB357	SATHESH. B	II nd	
9.	U15MB358	SATHIYA NARAYANA .S	II nd	
10.	U15MB359	SEDHUPATHY. S	II nd	
11.	U15MB360	SELVASRINIVASAN. B	II nd	
12.	U15MB361	SENTHILKUMARAN. A	II nd	
13.	U15MB362	SHAHARA ZAD .S	II nd	
14.	U15MB363	SHAKTHI. K	II nd	
15.	U15MB364	SHALINI. A	II nd	
16.	U15MB365	SHANMUGA PRIYANGA. A	II nd	
17.	U15MB366	SHARUMATHI.E	II nd	
18.	U15MB367	SHIYAM. M	II nd	
19.	U15MB368	SHRIRAAM .K	II nd	
20.	U15MB369	SIVA SAKTHI VELAN .A.V	II nd	


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Annexure III

MCQ PALLIATIVE CARE

1. All of the following are the key elements of palliative care except.
 - a. Pain and symptom management
 - b. Psychological and spiritual support
 - c. Getting the patients to be DNR
 - d. Co-ordination of care

2. Which of following is not a priority for patients with a life limiting illness receiving palliative care?
 - a. Relieving burden
 - b. Prolonging life at all costs
 - c. Obtaining a sense of control
 - d. Strengthening relationship with lovedone

3. The greatest increase in survival during palliative care has been associated with.
 - a. Heart failure
 - b. Breast cancer
 - c. Colorectal cancer
 - d. COPD

4. The main stay of pain management at the end of life is.
 - a. Radiotherapy
 - b. Psychological intentions
 - c. Pharmacotherapy
 - d. Spinal interventions

5. The effects of advance care planning on palliative care include thefollowing except.
 - a. Strengthened patients, autonomy
 - b. Decreased hope /net costs
 - c. Improved quality of care
 - d. Decreased post-operative stress and depression in family members

6. Criteria for palliative care.
 - a. Heart disease
 - b. Lung disease
 - c. AIDS
 - d. All the above

7. Barriers for initiating palliative care?
 - a. Lack of understanding
 - b. Lack of facilities
 - c. Both A&B
 - d. None of the above

8. Which of the following are radio frequency ablation to help in pain management at the end of life
 - a. Facet joint denervation
 - b. Spinal Cordotomy
 - c. Frozen shoulder
 - d. Ilio-inguinal neuropathy

9. Opioid of choice for intrathecal infusion for pain relief in palliative care
 - a. Morphine
 - b. Fentanyl
 - c. Oxycodone
 - d. Diamorphine

10. Which of the following has been found useful in trials on improving dyspnea on palliative care?
 - a. Breathing training
 - b. Neuro-electrical muscle stimulation
 - c. Chest wall vibration
 - d. All the above

SARATH KUMAR A

Annexure III

MCQ PALLIATIVE CARE

9
10

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SHRIRAMH - K.

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Annexure V

Student Feedback Form

Course Name: **PALLIATIVE CARE**

Subject Code: **ANAES 04**

Name of Student: _____ Roll No.: _____

We are constantly looking to improve our classes and deliver the best training to you.

Your evaluations, comments and suggestions will help us to improve our performance

Sl. NO	Particulars	1	2	3	4	5
1	Objective of the course is clear					
2	Course contents met with your expectations					
3	Lecturer sequence was well planned					
4	Lectures were clear and easy to understand					
5	Teaching aids were effective					
6	Instructors encourage interaction and were helpful					
7	The level of the course					
8	Overall rating of the course	1	2	3	4	5

*** Rating: 5 – Outstanding; 4 - Excellent; 3 – Good; 2– Satisfactory; 1 - Not-Satisfactory**

Suggestions if any:

Sandhya-T

Annexure V

Student Feedback Form

Course Name: PALLIATIVE CARE

Subject Code: ANAES 04

Name of Student: SANDHYA-T Roll No.: U15MB352

We are constantly looking to improve our classes and deliver the best training to you.

Your evaluations, comments and suggestions will help us to improve our performance

Sl. NO	Particulars	1	2	3	4	5
1	Objective of the course is clear				✓	
2	Course contents met with your expectations			✓		
3	Lecturer sequence was well planned				✓	
4	Lectures were clear and easy to understand					✓
5	Teaching aids were effective			✓		
6	Instructors encourage interaction and were helpful					✓
7	The level of the course					✓
8	Overall rating of the course	1	2	3	4	5

* Rating: 5 - Outstanding; 4 - Excellent; 3 - Good; 2 - Satisfactory; 1 - Not-Satisfactory

Suggestions if any:

Need more interactive studies

Annexure V

Student Feedback Form

Course Name: PALLIATIVE CARE

Subject Code: ANAES 04

Name of Student: SHRINUSAPRIYAGA Roll No.: U15HB365

We are constantly looking to improve our classes and deliver the best training to you.

Your evaluations, comments and suggestions will help us to improve our performance

Sl. NO	Particulars	1	2	3	4	5
1	Objective of the course is clear			✓		
2	Course contents met with your expectations				✓	
3	Lecturer sequence was well planned					✓
4	Lectures were clear and easy to understand				✓	
5	Teaching aids were effective			✓		
6	Instructors encourage interaction and were helpful					✓
7	The level of the course				✓	
8	Overall rating of the course	1	2	3	4	5

* Rating: 5 – Outstanding; 4 - Excellent; 3 – Good; 2– Satisfactory; 1 - Not-Satisfactory

Suggestions if any:

Need More Teaching Staff

Date: 04.05.22

From
Dr. Nithianandam
Professor and Head,
Department of Anaesthesia
Sri Lakshmi Narayana Institute of Medical Sciences
Puducherry

To
The Dean,
Sri Lakshmi Narayana Institute of Medical Sciences
Puducherry


Sub: Completion of value-added course: Palliative Care

Dear Sir,

With reference to the subject mentioned above, the department has conducted the value-added course titled: Palliative Care in Jan- 2022 for 20 students. We solicit your kind action to send certificates for all the participants, whose name list is attached with this letter. Also, I am attaching the photographs captured during the conduct of the course.

Kind Regards,

Dr.Nithianandam


Sri Lakshmi Narayana Institute of Medical Sciences,
Osudu, Kudapakkam, Puducherry - 605 502

Encl: Certificates

Photographs



Sri Lakshmi Narayana Institute of Medical Sciences

Affiliated to Bharath Institute of Higher Education & Research
(Deemed to be University under section 3 of the UGC Act 1956)



CERTIFICATE OF MERIT

This is to certify that SHARUMATHI E has actively participated in the Value Added Course on Palliative Care held during January - 2022 Organized by Sri Lakshmi Narayana Institute of Medical Sciences, Pondicherry- 605 502, India.


Dr. SUJARITHA
RESOURCE PERSON
DEPARTMENT OF ANAESTHESIOLOGY
SRI LAKSHMI NARAYANA INSTITUTE
OF MEDICAL SCIENCES
OSI/OU, KUDAPAKKAM, PUDUCHERRY-605 502


Dr. NITHIANANDAM S
Sri Lakshmi Narayana Institute of Medical Sciences
COORDINATOR
Pondicherry - 605 502.



Sri Lakshmi Narayana Institute of Medical Sciences

Affiliated to Bharath Institute of Higher Education & Research
(Deemed to be University under section 3 of the UGC Act 1956)



CERTIFICATE OF MERIT

This is to certify that SHRIRAM K has actively participated in the Value Added Course on Palliative Care held during January - 2022 Organized by Sri Lakshmi Narayana Institute of Medical Sciences, Pondicherry- 605 502, India.


Dr. SUJARITHA
RESOURCE PERSON

DEPARTMENT OF ANAESTHESIOLOGY
SRI LAKSHMI NARAYANA INSTITUTE
OF MEDICAL SCIENCES
OSUDU, KUDAPAKKAM, PUDUCHERRY-605 502


Dr. NITHIANANDAM S

COORDINATOR

Sri Lakshmi Narayana Institute of Medical Sciences
Osudu, Kudapakkam, Pondicherry - 605 502

