Palliative Care Manual for Healthcare Professionals in Sri Lanka

Second Edition

Palliative and End-of-Life Care Task Force
Sri Lanka Medical Association

Palliative Care Manual for Healthcare Professionals in Sri Lanka

Palliative and End-of-Life Care Task Force

Sri Lanka Medical Association

October 2021

ISBN NO -ISBN978-624-5972-03-6

Published by

Palliative & End-of-Life Care Task Force

Sri Lanka Medical Association

No 6, 'Wijerama House',
Wijerama Mawatha,
Colombo 07, Sri Lanka
Tel : +94112693324
Email : pctfslma@gmail.com

Printed by

KL Print Solutions

No. 2, Trelawney Place

Colombo 04, Sri Lanka

Cover designed by

Dr. Nirodha Jayawickrema

Message from the Director General Health Services, Sri Lanka

I am delighted to convey a message to the 2nd edition of the 'Palliative Care Manual for the Healthcare Professionals' published by the Palliative and End-of-Life Care Task Force of the Sri Lanka Medical Association (SLMA). This is an extension of the pioneer work done by the SLMA by publishing the first ever palliative care textbook dedicated to healthcare workers in Sri Lanka in 2017.

Palliative care has become a need of the hour due to increased chronic disease burden related suffering. Ministry of Health has identified palliative care as a priority area and strived with other stakeholders to improve the quality of the services offered to our patients. The SLMA is one of our key stakeholders which has always volunteered to support the Ministry in its activities.

The SLMA has made a significant contribution to the field of palliative care in Sri Lanka and played an advocacy role to the Ministry of Health since the inception of the palliative care task force. The members of the Palliative Care Task Force have represented the National Steering Committee for Palliative Care and have been instrumental in launching the National Palliative Care Strategic Frame Work. SLMA has taken a leading role in building palliative care teams in the state hospitals and training them with the help of the National Cancer Control Programme. This book would further strengthen dissemination of knowledge to the palliative care teams by providing updated guidance.

I truly believe that Palliative Care Manual for the Healthcare Professionals would improve the knowledge of palliative care among health care professionals and improve the quality of palliative care services in the country.

While congratulating the members of the Palliative and End-of-Life Care Task Force of the SLMA for this achievement, I pledge maximum support of the Ministry of Health in all your endevours.

With best wishes,

Dr Asela Gunawardene
Director General of Health Services
Ministry of Health, Sri Lanka

Message from the President, Sri Lanka Medical Association

The prime objective of palliative care is relieving suffering in all stages of diseases. Palliative care encompasses both malignant and non-malignant conditions and a wide spectrum of issues that require an interdisciplinary care delivery. The Ministry of Health has identified palliative care as a priority area as it ensures the best possible quality of life for the patients with life-limiting illnesses and their families. In line with that, Sri Lanka Medical Association established a task force for the palliative and End-of-life care, which is now functioning as an independent expert committee and working with Ministry of Health to uplift the palliative care in Sri Lanka.

One of the very first achievements of the Palliative and End-of-life Care Task Force in year 2017 was formulating a manual for management of non-cancer patients as a guidance to the health care professionals to control symptoms. Now the task force has come forward with a broad and improved second edition of the same, 'Palliative Care Manual for Healthcare Professionals in Sri Lanka', which includes management guidance for cancer patients as well. The book emphasizes not only about controlling physical symptoms but also on the psychological and social issues of life limiting illness, where patient values and preferences must be respected. It has also been included essential skills needed in palliative care such as communication and teamwork.

On behalf of the Sri Lanka Medical Association, I congratulate our highly energetic Palliative and End-of-Life Care Task Force for working on the second edition of a complete guidebook for the easy reference of all practicing health professionals in Sri Lanka. This user-friendly book will also

help every care team in establishing individualized goals of care. A special thank is deserved by the Task Force for sharing their expertise and experience meticulously and taking their time voluntarily to develop this manual in this difficult and unprecedented era.

I am more than confident that this effort would enable the best of care for our patients in need.

Dr Padma S Gunaratne

President - Sri Lanka Medical Association

(2020-2021)

Message from Prof Chandrika Wijeyaratne, Founder of the Palliative and End-of-Life Care Task Force

It is estimated that by 2060, half of the world's deaths will involve serious health related suffering, and 83% of these deaths will take place in low and middle income countries[1]. As things stand, fifty percent of the world does not have access to palliative care[2].

Given this context, Sri Lanka is blessed to have a group of passionate physicians who recognise the value of integrating palliative care into our health system. As committed groups of members of the Palliative Care Task Force of the Sri Lanka Medical Association, many of you have given of your time and expertise to make this a reality and for no personal gain.

Creating a medical specialty from scratch is exciting but comes with challenges. The term 'palliative care' can have negative connotations to many people, given that it can signal a failure of treatment, and involves the use of medications that are considered dangerous and addictive. Introducing palliative care to the country involves the engagement of healthcare professionals as well as the public. It requires a change in mindset regarding failure and success, and what life and death means to our society.

In the current era of medicine, there are few specialties that have the luxury of being allowed to treat a person rather than a set of numbers or scans. There are also few instances where the priority of a consultation or ward round is to understand the person in front of us, their family, their understanding, their wishes, and to relieve suffering. The burden of treatment is balanced against the burden of symptoms. This requires time, empathy and practise. It forces us to use our clinical acumen, and make considered decisions regarding investigations and management. It brings us back to the person sitting in front of us.
Many aspects that are central to palliative care form the basis of any good clinical practice- however as medicine continues to subspecialise and time becomes an ever more scarce resource, the integration of palliative care medicine into our daily practice requires a sharper focus.

I am confident that this updated book provides you with some of the tools to assist you in integrating palliative care into your day to day care of patients and their families.

1. Sleeman KE, de Brito M, Etkind S et al. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. Lancet Glob Health. 2019; doi.org/10.1016/S2214-109X(19)30172-X

2. Lynch T, Connor, S Clark D. Mapping levels of palliative care development: a global update. J Pain Symptom Manage. 2013; 45: 1094-1106

Prof Chandrika Wijeyaratne
Past President - SLMA
Vice Chancellor - University of Colombo

CONTENTS

PREFACE

Palliative care is an emerging multi-disciplinary field in Sri Lanka. There is an increasing demand for palliative services in this country. Therefore, we as members of the Palliative and End-of-Life Care Task Force of the SLMA realized the need to disseminate knowledge, develop skills and attitudes in palliative care among the healthcare professionals.

The Palliative and End-of-Life Care Task Force is an independent expert committee of the Sri Lanka Medical Association and our aim is to provide a practical guide to medical professionals in providing high standard holistic care in their day-to-day practice of patients with life threatening and life limiting illnesses.

The first edition of *'Palliative care Manual for Management of Non- cancer patients - A Guide for Healthcare Professionals'* was published in 2017. In this subsequent edition, *'Palliative Care Manual for Healthcare Professionals in Sri Lanka',* we have addressed management of both cancer and non-cancer palliative patients. The book will provide easy reference to clinical scenarios among patients in hospital and community settings.

This book contains views of multiple authors from different disciplines related to palliative care. We thank all of them and the editors for their diligence and commitment.

Dr. Dilhar Samaraweera
Chairperson
Palliative & End-of-Life
Care Task Force

Dr. Udayangani Ramadasa
Convener
Palliative & End-of-Life
Care Task Force

AUTHORS

Dr. G. Udayangani Ramadasa
MBBS - *(Col),* MD - Medicine *(Col)*, Dip Pall Med - Clinical *(RACP)*, FCCP
Specialist in Internal Medicine
Head and Senior Lecturer, Department of Medicine
Faculty of Medicine, Sabaragamuwa University of Sri Lanka

Dr. Dilhar Samaraweera
MBBS, MD (*Col*), MRCP*(UK),* FRCP *(Lond)*, FCCP,
PgD Geriatric Medicine *(Glasgow)*
Consultant Physician
Colombo South Teaching Hospital, Kalubowila

Dr. Ravini de Silva Karunatillake
MBBS, MD, MRCP
Consultant Respiratory Physician
National Hospital of Sri Lanka, Colombo

Dr. Sampath Kondasinghe
MBBS, FRACP, FAChPM
Palliative Care Specialist and Consultant Physician
Royal Perth Hospital, Australia

Dr. Gamini Pathirana
MBBS, MD, FCCP
Specialist in Neurology
National Hospital of Sri Lanka, Colombo

Dr. Hasitha Wijewantha
MBBS *(Col)*, MD *(Col)*, MRCP *(UK)*, MRCP *(Lond)*
Consultant Gastroenterologist
Teaching Hospital, Rathnapura

Prof. Piyanjali de Zoysa
BA (Hons) Psychology, MA (Applied Psychology), PhD
Clinical Psychologist and Professor in Clinical Psychology
Department of Psychiatry
Faculty of Medicine, University of Colombo

Dr. Nilesh Fernandopulle

MBBS(*Col*), MD(*Col*), FRCP (*Lond*), Speciality certificate in Gastroenterology*(UK),*
Pg in Med Edu (*Col*)
Consultant Gastroenterologist & Senior Lecturer
Department of Surgery
University Surgical Unit, National Hospital of Sri Lanka.

Dr. Gayani P. Gamage

BSc, MSc, PhD - Psychology, CPsychol *(UK)*
Senior Lecturer
Department of Psychology & Counselling
The Open University of Sri Lanka, Nugegoda

Dr. Kalyani Guruge

MBBS, MD - *Paed*
Specialist Paediatrician

Dr. Chinthaka Hathlahawatta

MBBS, MD Consultant Cardiologist
Teaching Hospital Ratnapura

Prof. Panduka Karunanayake

MBBS *(NCMC),* MD - General Medicine *(Col),* FRCP *(Lon),* FCCP *(SL)*, PgD Applied Sociology *(Col)*
Specialist Physician and Professor in Clinical Medicine
Department of Clinical Medicine
Faculty of Medicine, University of Colombo

Dr. Clifford Perera

MBBS(*Col*), DLM, MD(*Col*), MA(*Kel*), LLB, DMJ(*Lond*), MFFLM(*UK*)
Attorney-at-Law
Board certified Specialist in Forensic Medicine and Senior Lecturer
Dept. of Forensic Medicine
Faculty of Medicine, University of Ruhuna, Galle

Dr. Suraj Perera

MBBS, MSc, MD
Specialist in Community Medicine
National Canceaar Control Programme
Ministry of Health, Sri Lanka

Dr. Sanjeewa Rajapakse
MBBS, MD, MRCP
Specialist Cardiologist
Colombo North Teaching Hospital, Ragama

Dr. Mahesh Rajasuriya
MBBS, MD (Psychiatry)
Senior Lecturer, Department of Psychiatry
Faculty of Medicine, University of Colombo
Consultant Psychiatrist, National Hospital of Sri Lanka

Dr. Sankha Randenikumara
MBBS *(SJP),* MCGP *(SL),* PgDTox *(Col),*
PgD Archaelogy *(Kel),* FPallCare *(IPM)*
Family Physician - The Family Health Clinic, Wattala
Medical Officer - Planning & Quality Management Unit
Base Hospital, Panadura

Dr. K. V. C. Janaka
MBBS, MD
Consultant Physician
Sri Jayewardenepura General Hospital, Nugegoda

Dr. Jalitha Thinnarachchi
MBBS *(SJP),* MD *(Col)*
Specialist in Nephrology and Transplant Medicine,
Teaching Hospital Ratnapura

Dr. Ranga E Wickramarachchi
MBBS(*SJP*), MD *(Col)*, MRCS *(Eng)*
Specialist in Urological Surgery and Senior Lecturer
Department of Clinical Sciences
Faculty Medicine, General Sir John Kotelawala Defence University

Prof. Shyamalee Samaranayaka
MBBS, DFM, DCH, MD - Family Medicine, MRCGP *(Int),* FCGP
Specialist Family Physician and Professor in Family Medicine
Department of Family Medicine
Faculty of Medical Sciences, University of Sri Jayewardenepura

Dr. Nipunika Senadheera
MBBS, D.Path, MD - Haematology
Consultant Haematologist
Lady Ridgeway Hospital for Children, Colombo

Dr. Manilka Sumanatilleke
M.BBS, MD *(Col),* MRCP (*Lon),* MRCP - *Diab & Endo (UK),*
FRCP (*Edin)*, FACE *(USA),* FSLCE *(SL)*
Consultant Endocrinologist
National Hospital of Sri Lanka, Colombo

Dr. Arjuna Marasinghe
MBBS, MD, MRCP*(UK)*
Consultant Nephrologist
Colombo South Teaching Hospital, Kalubowila

Dr. Angela de Silva
BsC, MBBS, PhD
Nutrition Specialist

Dr Thushari D. Hapuarachchi
MBBS, MD
Consultant Clinical Oncologist
Apeksha Hospital, Maharagama

Dr Sujeewa Weerasinghe
MBBS, MD
Consultant Clinical Oncologist
Apeksha Hospital, Maharagama

Dr. Gayani Walpola
MBBS, MD
Consultant Anaesthetist
Apeksha Hospital, Maharagama

Dr. Shanika Vitharana
MBBS, D.Path, MD - Haematology, FRCPath (*UK*)
Consultant Haematologist
Lady Ridgeway Hospital for Children, Colombo

Dr. Nadishani Ediriwickrama
MBBS, MD - Clinical Haematology, FRCPath*(UK)*
Consultant Haematologist
Castle Street Hospital for Women, Colombo

Prof. Senani Williams
MBBS, D.Path, MD - Haematology, FRCPath(*UK*)
Consultant Haematologist and Professor in Pathology
Department of Pathology
University of Kelaniya

Dr. Nipun Lakshitha de Silva
MBBS, MD
Senior Registrar in Endocrinology and Lecturer
Department of Clinical Medicine
Faculty of Medicine, General Sir John Kotelawala Defence University

Dr. Uthpala Attygalle
MBBS(*Ruhuna*) DLM MD*(Col)* DFM*(RCPA)*
Board certified Specialist in Forensic Medicine
Base Hospital Panadura

Dr. Rohini Ranwala
MBBS, MD - Anaesthesia, FCARCS
Specialist in Anaestheseology

Dr. Anula Rathnayake
BA *(Col),* MA *(Col),* PhD *(Slov)*
Senior Lecturer in Social Work
Department of Psychiatry
Faculty of Medicine, University of Colombo

Dr. C. M. Asela Anthony
MBBS, DFM, MD - Family Medicine (*Col*), MRCGP (*INT*), MCGP (*SL*)
DAvM, DOH&S
Specialist in Family Medicine and Senior Lecturer
Faculty of Medicine, University of Colombo

EDITORS

Dr. Udayangani Ramadasa
MBBS, MD - Medicine, Dip Pall Med - Clinical *(RACP),* FCCP
Specialist in Internal Medicine, Head and Senior Lecturer
Department of Medicine
Faculty of Medicine, Sabaragamuwa University of Sri Lanka

Prof. Panduka Karunanayake
MB BS (NCMC), MD General Medicine (Col), FRCP (Lon), FCCP (SL), PGDip Applied Sociology (Col).
Specialist Physician and Professor in Medicine
Department of Clinical Medicine
Faculty of Medicine, University of Colombo

Dr. Ravini de Silva Karunatillake
MBBS, MD, MRCP
Consultant Respiratory Physician
National Hospital of Sri Lanka, Colombo

Dr. Gamini Pathirana
MBBS, MD, FCCP
Specialist in Neurology
National Hospital of Sri Lanka, Colombo

Prof. Antoinette Perera
MBBS, DFM, MD - *Family Medicine*, FCGP, FRCGP *(Hon),* FWONCA
Specialist Family Physician and Emeritus Professor of Family Medicine
University of Sri Jayewardenepura

Prof. Priyadarshani Galappatthy
MBBS *(Col),* MD *(Col)*, MRCP *(UK),* FRCP *(Lond)*, FCCP, DipMedTox *(Cardiff)*
Specialist in General Medicine, Senior Professor and Chair Professor of Pharmacology
Department of Pharmacology
Faculty of Medicine, University of Colombo.

Dr. Dilhar Samaraweera
MBBS, MD (*Col*), MRCP*(UK),* FRCP *(Lond)*, FCCP,
PgD Geriatric Medicine *(Glasgow)*
Consultant Physician
Colombo South Teaching Hospital, Kalubowila

Prof. Nirmala Wijekoon
MBBS, MD, MRCP *(UK),* FRCP, FRCPE, FCCP
Specialist in Internal Medicine and Professor in Pharmacology
Faculty of Medical Sciences, University of Sri Jayewardenepura

DISCLAIMER

Information provided in this book are to assist health care professionals by providing guidance and recommendations for particular areas of practice. This guide should not be considered inclusive of all approaches or methods or exclusive of others. The guide cannot guarantee any specific outcome, nor does it establish a standard of care. This manual is not intended to dictate the treatment of a particular patient. Treatment decisions must be made based on the independent judgment of health care providers and each patient's individual circumstances.

The publisher, authors, or the Sri Lanka Medical Association make no warranty, expressed or implied, regarding information and specifically excludes any warranties of merchantability and fitness for a particular use or purpose and also shall not be liable for direct, indirect, special, incidental or consequential damages related to the use of the information contained herein.

Bibliography is provided for informational purposes only and not to constitute endorsement of any website or other sources. Readers should be aware that the web information listed in this book may change.

Section 1

INTRODUCTION

CHAPTER 1

What is Palliative Care?

Palliative care is the multi-disciplinary specialty that provides care to patients who are having a disease that is no longer curable. The goal is to improve the patient's quality of life, by alleviating suffering and providing relief to the patient's problems in the physical, psychological, social and spiritual domains.

Palliative care core values

- It gives a support system to the patient to live as actively as possible during the course of the illness.
- It offers a support system to the family to cope during this difficult period and during bereavement.
- It affirms life and regards death as a normal process.
- It anticipates problems and aims to minimize the impact of the progressing illness.
- It is holistic care, relieving physical social, psychological and spiritual suffering
- It is interdisciplinary in nature

Factors to consider when providing an effective support system in palliative care

The need to understand:

- The meaning of illness
- Its effect on the individual
- Its effects on the caregivers and to acknowledgement their concerns and sources of distress
- How to respond to them effectively.

Difficult symptoms do not suddenly appear in the last days of life; they are often present throughout the patient's illness. Palliative care services need to be introduced early in the course of an illness, and they will continue even after the death of the patient. Palliative care may be provided at any point along the disease continuum, from diagnosis to the end of life. It should integrate with usual care, while the patient is receiving disease-modifying treatment.

Palliative care should be provided by the relevant specialist team and augmented as needed by collaboration with an interdisciplinary team of palliative care experts. The time to start palliative care is as soon as a diagnosis of life limiting/threatening illness is made.

To enable the provision of palliative care:

- All health care professionals should receive education and training to develop palliative care knowledge, skills, and attitudes
- An interdisciplinary team of palliative care specialists should be available, to provide consultation or direct care to patients and/or families as requested or needed
- The quality of palliative care should be monitored by institutional quality improvement programs

Appropriate care in patients with life-threatening illnesses.

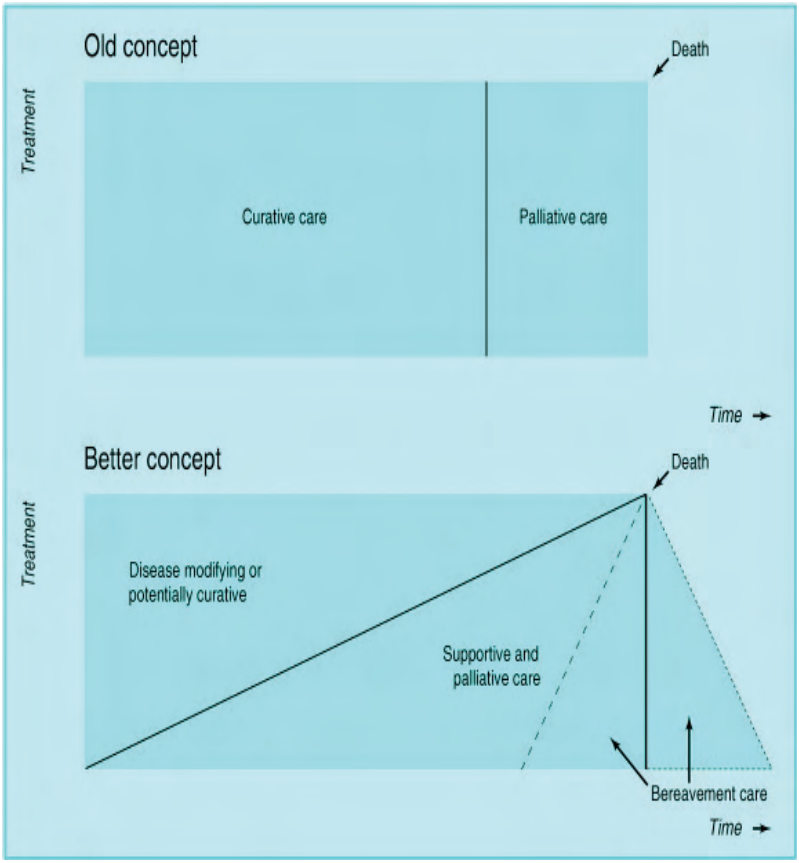


Figure 1: Murry (2005)

Essential components of palliative care

- Building rapport and relationships with patients and family caregivers
- Managing symptoms, distress, and functional status (e.g., pain, dyspnoea, fatigue, sleep disturbance, mood, nausea, constipation)
- Exploration of understanding and education about illness and prognosis
- Clarification of treatment goals
- Assessment and support of coping needs (e.g., provision of dignity and therapy)
- Assistance with medical decision-making
- Coordination with other care providers
- Provision of referrals to other care providers as indicated

Providing palliative care requires a comprehensive assessment of the patient's and family's problems, with an emphasis on the quality of life, leading to a care plan. Suffering is universal, but its exact form is unique to each individual. Interventions should focus on alleviating suffering of either one or several of four domains, i.e. physical (Box 1), psychological (Box 2), social (Box 3) and spiritual (Box 4). A comprehensive assessment should be done on a regular basis at reasonable intervals, and in response to significant changes in the patient's status.

Box 1

Physical domain

- Performance of activities of daily living
- Physical symptoms
- Nutrition and hydration
- Physical safety (falls)

Box 2

Psychological domain

- Emotions
- Cognition
- Mood
- Copying style
- Fears
- Dreams that are shattered

Box 3

Social domain

- Loneliness
- Economic
- Caregiver burden in the family
- Supportive network
- Patient and home environment
- Community environment

Box 4

Spiritual domain

- Meaning of life
- Religion
- Multiple hopes
- Multiple losses

Palliative care should come early in the course of illness and it should continue even after the death of the patient.

Palliative care is dynamic, and care needs and goals would change with the progression of the concurrent disease. (Box 5)

Box 5

Palliative care goals

- Prolongation of survival
- Optimization of function
- Optimization of comfort
- Bereavement care

There can be several goals concurrently

The care plan is based upon an ongoing assessment and setting up goals with the patients and caregivers, in collaboration with the multi-professional team.

To develop a care plan it is vital to understand the pattern of disease progression of each disease, considering other contributing factors such as age, co-morbidities, and level of care needed. Distinct pattern of illness trajectories has been identified for people with life-limiting illness.

Physical illness trajectories of chronic progressive diseases

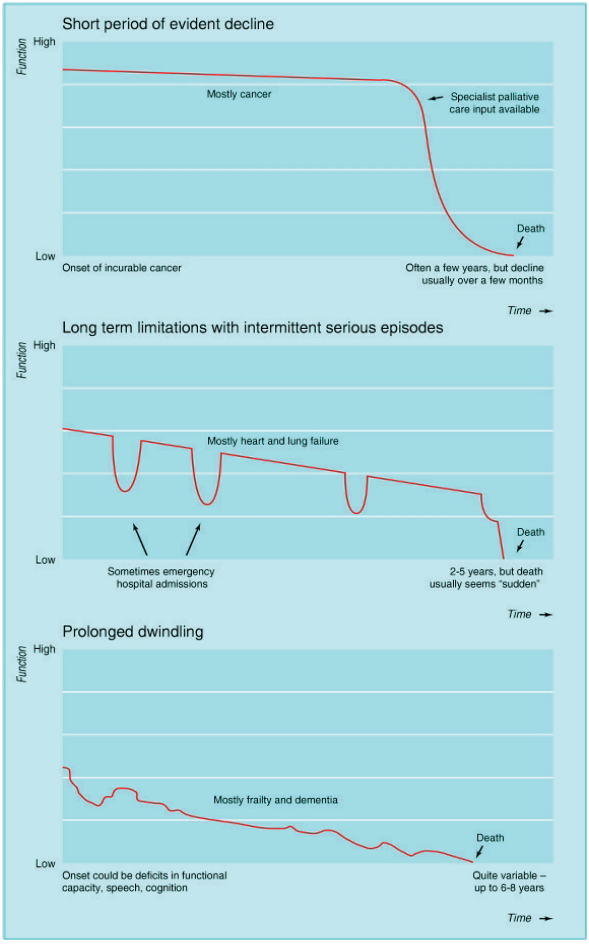


Figure 2: Murry (2005)

Understanding illness trajectories would help to optimize quality of life, by having a realistic dialogue about the disease outcome, options of supportive care, and symptom control and thereby planning a timely, dignified and peaceful death.

- Cancer patients are having a short illness trajectory, once diagnosed with metastatic cancer.
- Patients with organ failure will have exacerbations and remissions while baseline gradual functional decline. Each exacerbation carries the likelihood of death.
- Patients with dementia, old age would have prolonged dwindling, and they would die with problems such as sepsis, aspiration pneumonia or fall.

Not only physical function, but even the psychological aspect, social aspect and spiritual aspect would change, in different ways, with the progression of different illnesses. (Fig 3 and 4)

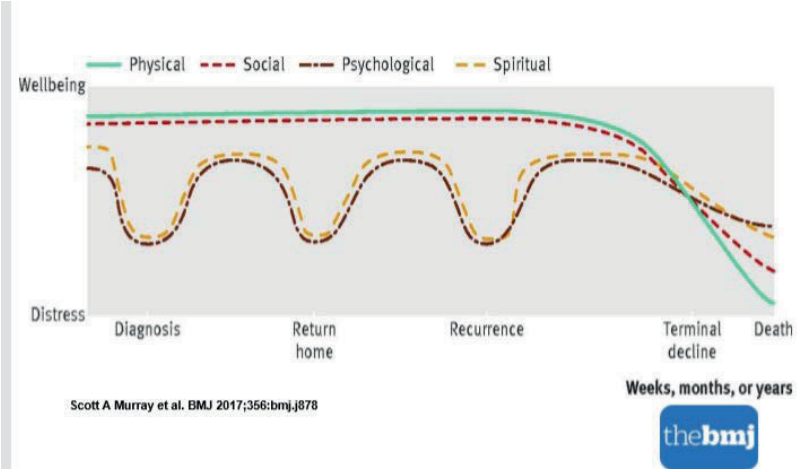


Fig 3: Wellbeing trajectories in patients with rapid functional decline (eg; cancer) (Murray et al, 2007)

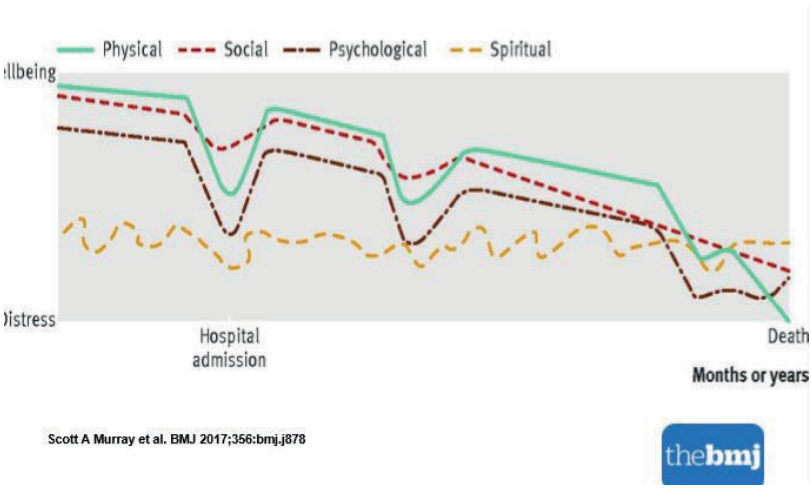


Fig 4: Wellbeing trajectories in patients with intermittent decline (eg: organ failure) (Murray et al, 2007)

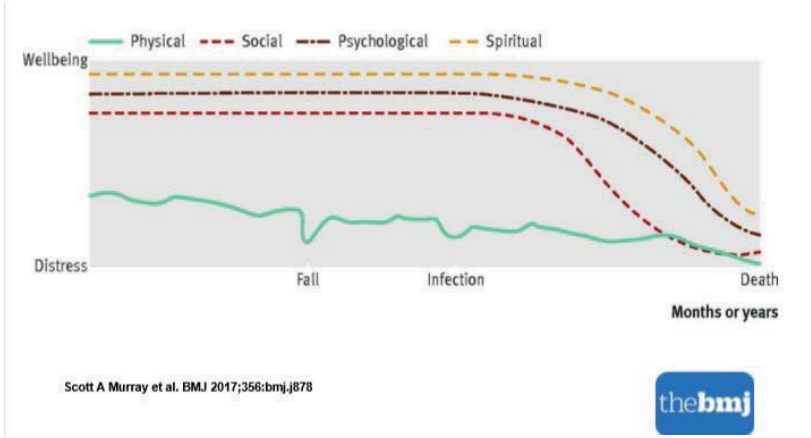


Fig 5: Wellbeing trajectories in patients with gradual decline (eg; frailty) (Murray et al, 2007)

The following figure (Fig 6) shows family and care givers wellbeing in patients with lung cancer.

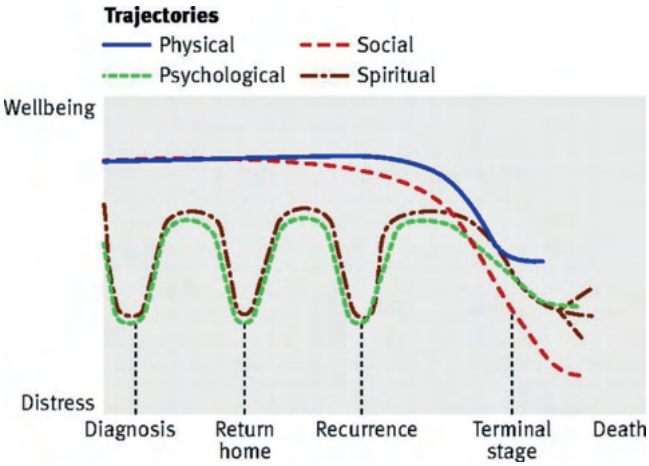


Fig 6: Family and care givers wellbeing in patients with lung cancer (Murray et al, 2007)

Identifying problems and setting up goals

Goals of care in individual patients will depend on the stage of the disease, the natural course of the illness and the patient's wishes. Goals such as prolongation of survival, optimisation of function and comfort and bereavement care could be amended with the progression of disease. There can be several goals concurrently. During the course of the active illness, active treatments such as antibiotics, dialysis, surgery or disease-modifying treatments may be given. With progression of the disease there may be more emphasis on the goals of improving symptoms and quality of life. Close to the terminal phase, comfort and bereavement care plays a major role.

Identification of correct goals for the individual is an important skill for a healthcare professional to acquire. Healthcare professionals

need to work with the patient to develop goals of care that target patient's needs, values and preferences. (Box 6)

Box 6

Factors to consider when setting up goals

- Natural course of the underlying illness
- Other comorbidities
- Stage of the disease
- Severity of symptoms
- Impact on quality of life
- The services available
- Concerns and needs of the patient and the care giver

Changes in the care plan are based on evolving needs during the progression of disease, preferences of the patient and family, and recognizing the complex, competing, and shifting priorities in goals of care.

Treatments and the care plan (with alternative options in view of the changing nature of the disease in the future), need to be clearly documented after discussions with the patient and family members, in a manner that promotes shared decision-making.

The palliative care programme is committed to providing a high quality of care and support for all patients with incurable disease and their families, by regular systematic assessment, analysis, goal-setting, review and evaluation, and revision of the process and outcomes of care.

Functional status of the patient

A person's functional status comprises several dimensions (Box 7)

Box 7

Components of functional status

- Cognitive functioning: e.g., attention, concentration, memory, problem solving
- Behavioral functioning: e.g., bathing, dressing, feeding, instrumental activities, shopping, cooking
- Psychological functioning: e.g., Mood, affect, motivation
- Social functioning: e.g., roles at home, work place, in the community

Principles of physical symptom control

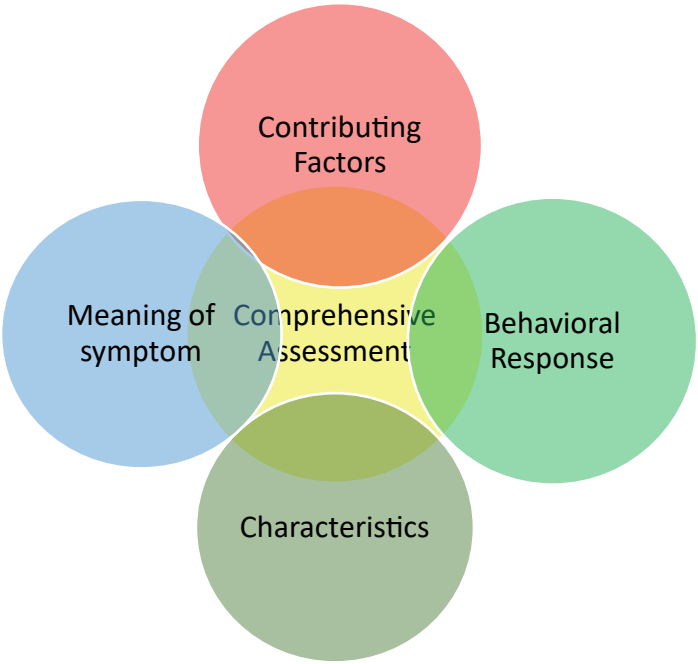
People with life-limiting illnesses may experience a range of symptoms and clinical problems depending on the underlying pathology of the disease, comorbidities and other psychological, social and environmental factors.Some common symptoms include, fatigue, pain, breathlessness, anorexia, constipation and emotional distress.

Key points to consider in life-limiting illnesses

- Symptoms do not always follow a predictable pattern
- Symptoms are always subjective, as they will be experienced differently by each person
- Symptoms are multifactorial

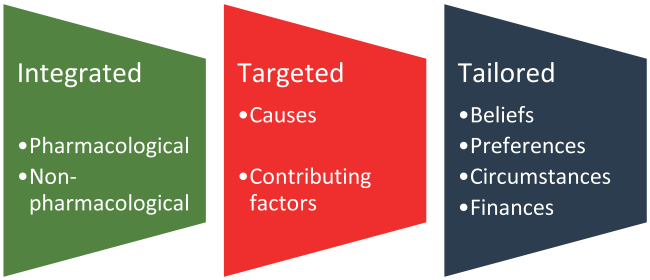
.

In order to identify the focus of intervention, comprehensive assessment of contributing factors, characteristics of symptoms, meaning of the symptoms to the patient and behavioural response to symptoms have to be identified.



In management, pharmacological and non-pharmacological methods should be integrated, and it should be targeted according to the underlying causes and contributing factors. Defining quality of life for each individual is different, and the management shouldbe tailored according to patient's values and preferences.

Approach to effective management



Definition of End of Life Care (General Medical Council, UK 2010)

People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions
- General frailty and co-existing conditions that mean they are expected to die within 12 months
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life-threatening acute conditions caused by sudden catastrophic events.

Predicting needs

We need to focus on predicting needs rather than exact prognostication. With the progression of the illness, it is important to anticipate likely needs so that the right care can be provided at the right time.

Three triggers that suggest that patients are nearing the end of life are: (based on **Prognostic Indicator Guidance (PIG) 4th Edition Oct 2011 © The Gold Standards Framework Centre in End of Life Care CIC, Thomas.K et al)**

1. The Surprise Question: 'Would you be surprised if this patient were to die in the next few months, weeks, days?

2 General indicators of decline: deterioration, increasing need or choice for no further active care.

3. Specific clinical indicators related to certain conditions.

General indicators of decline and increasing needs

- Decreasing activity: functional performance status declining (e.g. Barthel score, limited self-care, in bed or chair 50% of day) and increasing dependence in most activities of daily living
- Co-morbidity is regarded as the biggest predictive indicator of mortality and morbidity
- General physical decline and increasing need for support
- Advanced disease: unstable, deteriorating, complex symptom burden
- Decreasing response to treatments, decreasing reversibility
- Choice of no further active treatment
- Progressive weight loss (>10%) in past six months
- Repeated unplanned/crisis admissions

- Sentinel event: e.g. serious fall, bereavement, transfer to nursing home
- Serum albumin

Functional Assessments

- Barthel Index describes basic Activities of Daily Living (ADL) as 'core' to the functional assessment: e.g., feeding, bathing, grooming, dressing, continence, toileting, transfers, mobility, coping with stairs etc. (*Refer Chapter 21*)
- Karnofksy Performance Status Score 0-100 ADL scale.

Activities of Daily Living (ADLs) components in Katz Index of Independence in Activities of Daily Living

- **Personal hygiene**
  Bathing, grooming, oral, nail and hair care
- **Continence management**
  A person's mental and physical ability to properly use the bathroom
- **Dressing**
  A person's ability to select and wear proper clothes for different occasions, physically dress and undress oneself, ability to get on and off the toilet and clean oneself
- **Feeding**
  Whether a person can feed themselves or needs assistance (though not necessarily the capability to prepare food)
- **Ambulating/ transfer/mobility**
  The extent of a person's ability to change from one position to another and to walk independently. Ability to stand from sitting position, get out of bed, walk independently

Instrumental Activities of Daily Living (IADLs) components in Lawton - Brody Instrumental Activities of Daily Living Scale (I.A.D.L.)

Person's ability to live independently and thrive.

- **Companionship and mental support**
  This is a fundamental and a much-needed IADL. It reflects on the help that may be needed to keep a person in a positive frame of mind.
- **Transportation and shopping**
  How much a person can go around or obtain their grocery and pharmacy needs without help, ability to use public transport, drive or cycle, ability to make appropriate food and clothing purchasing decisions.
- **Preparing meals**
  Planning and preparing various aspects of meals, including cooking, cleaning up, ability to use kitchen equipment and utensils safely, shopping and storing groceries
- **Managing a person's household/ house work**
  Cleaning, tidying up, removing trash and clutter, and doing laundry and folding clothes, washing dishes, dusting

- WHO/ECOG Performance Status 0-5 scale of activity.

ECOG Performance status

0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all selfcare but unable to carry out any work activities; up and about more than 50% of waking hours
3	Capable of only limited selfcare; confined to bed or chair more than 50% of waking hours
4	Completely disabled; cannot carry on any selfcare; totally confined to bed or chair
5	Dead

Karnofsky Performance Scale

Able to carry on normal activity and to work; no special care needed.	100	Normal no complaints; no evidence of disease.
Able to carry on normal activity and to work; no special care needed.	90	Able to carry on normal activity; minor signs or symptoms of disease.
Able to carry on normal activity and to work; no special care needed.	80	Normal activity with effort; some signs or symptoms of disease.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	70	Cares for self; unable to carry on normal activity or to do active work.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	60	Requires occasional assistance, but is able to care for most of his personal needs.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	50	Requires considerable assistance and frequent medical care
Unable to care for self; requires equivalent of institutional or hospital care;	40	Disabled; requires special care and assistance.

disease may be progressing rapidly		
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly	30	Severely disabled; hospital admission is indicated although death not imminent.
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly	20	Very sick; hospital admission necessary; active supportive treatment necessary.
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly	10	Moribund; fatal processes progressing rapidly.
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly	0	Dead

Indications for the need of palliative care in cancer patients

The National Comprehensive Cancer Network (NCCN) recommends assessment by the oncology team for patients whose screening confirms the presence of one or more of the following

- Uncontrolled symptoms
- Moderate-to-severe distress related to cancer diagnosis and cancer therapy
- Serious comorbid physical, psychiatric, and psychosocial conditions
- Patient, family, or caregiver concerns about the course of disease and decision-making
- Patient/family requests for palliative care
- Metastatic solid tumours and refractory hematologic malignancies
- Potentially life-limiting disease

- Poor performance status: Eastern Cooperative Oncology Group (ECOG) score ≥3 or Karnofsky Performance Status (KPS) score ≤50
- Persistent hypercalcemia
- Brain or cerebrospinal fluid metastasis
- Delirium
- Malignant bowel obstruction
- Superior vena cava syndrome
- Spinal cord compression
- Cachexia
- Malignant effusions
- Palliative stenting or venting gastrostomy

Cancer specific management including chemotherapy and radiotherapy is an essential component of palliative care intervention in physical symptom management of cancer patients.

Prognostic Indicator Guidance (PIG) 4th Edition Oct 2011 © The Gold Standards Framework Centre in End of Life Care CIC, Thomas K. et al

In erratic decline/organ failure

Chronic Obstructive Pulmonary Disease (COPD)

At least two of the indicators below:

- Disease assessed to be severe (e.g. FEV1 <30% predicted)
- Recurrent hospital admissions (at least 3 in last 12 months due to COPD)
- Fulfils long term oxygen therapy criteria
- MRC grade 4/5: shortness of breath after 100 metres on the level of confined to house
- Signs and symptoms of right heart failure
- Combination of other factors: i.e. anorexia, previous ITU/NIV resistant organisms
- More than 6 weeks of systemic steroids for COPD in preceding 6 months.

Heart Disease

At least two of the indicators below:

- CHF NYHA Stage 3 or 4: shortness of breath at rest on minimal exertion
- Patient thought to be in the last year of life by the care team: the 'surprise question'
- Repeated hospital admissions with heart failure symptoms
- Difficult physical or psychological symptoms despite optimal tolerated therapy.

Renal Disease

Stage 4 or 5 Chronic Kidney Disease (CKD) whose condition is deteriorating with at least 2 of the indicators below:

- Patient for whom the surprise question is applicable
- Patients choosing the 'no dialysis' option, discontinuing dialysis or not opting for dialysis if their transplant has failed
- Patients with difficult physical symptoms or psychological symptoms despite optimal tolerated renal replacement therapy
- Symptomatic Renal Failure: nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload.

General Neurological Diseases

- Progressive deterioration in physical and/or cognitive function despite optimal therapy
- Symptoms which are complex and too difficult to control
- Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure
- Speech problems: increasing difficulty in communications and progressive dysphasia.

Plus, the following:

Motor Neuron Disease

Marked rapid decline in physical status

- First episode of aspirational pneumonia
- Increased cognitive difficulties
- Weight loss
- Significant complex symptoms and medical complications
- Low vital capacity (below 70% of predicted using standard spirometry)
- Dyskinesia, mobility problems and falls
- Communication difficulties.

Parkinson's Disease

- Drug treatment less effective or increasingly complex regime of drug treatments
- Reduced independence, needs ADL help
- The condition is less well controlled with increasing "off" periods
- Dyskinesias, mobility problems and falls
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)
- Similar pattern to frailty- see below.

Multiple Sclerosis

- Significant complex symptoms and medical complications
- Dysphagia + poor nutritional status
- Communication difficulties, e.g., dysarthria + fatigue
- Cognitive impairment notably the onset of dementia.

Frailty/dementia: gradual decline

Frailty

Individuals who present with multiple co morbidities with significant impairment in day-to-day living and:

- Deteriorating functional score, e.g., performance status – Barthel/ECOG/Karnofksy
- Combination of at least three of the following symptoms:
- weakness
- slow walking speed
- significant weight loss
- exhaustion
- low physical activity
- depression

Dementia

There are many underlying conditions which may lead to degrees of dementia and these should be taken into account. Triggers to consider that indicate that someone is entering a later stage are:

- Unable to walk without assistance and
- Urinary and faecal incontinence, and
- No consistently meaningful conversation and
- Unable to do Activities of Daily Living (ADL)
- Barthel score <3.

Plus, any of the following:

- Weight loss
- Urinary tract infection
- Severe pressures sores: stage 3 or 4
- Recurrent fever
- Reduced oral intake
- Aspiration pneumonia.

It is vital that discussions with individuals living with dementia are started at an early stage, whilst they have mental capacity, to ensure that they can discuss how they would like the later stages managed.

Stroke

- Persistent vegetative or minimal conscious state or dense paralysis
- Medical complications
- Lack of improvement within 3 months of onset
- Cognitive impairment/post-stroke dementia.

Spiritual care

> "Spirituality is the way we seek and express meaning and purpose; the way we experience our connection to the moment, self, others, our world and the significant or sacred. Spiritual care occurs in a compassionate relationship. It responds to our search for meaning, self-worth, and our need to express ourselves to a sensitive listener".
>
> Joint position statement from Palliative Care Australia and Meaningful Ageing Australia in May 2017,

Spiritual care is an integral part in palliative care. In palliative care we need to respect and honour individual understanding beliefs promoting and encouraging conversations rather than distinctions.

Spirituality is not religiousness; however, positive religious coping has shown positive outcome in improvement of quality of life, in patients in end of life.

Spirituality is a patient need. It affects healthcare decision-making, and healthcare outcomes including quality of life. Spiritual and religious beliefs can also create distress and increase the burdens of illness. The palliative care team should regularly explore spiritual and existential concerns and document these spiritual themes in order to communicate them to the team. This exploration includes, but is not limited to:

- life review
- assessment of hopes, values, and fears, meaning, purpose
- beliefs about afterlife
- spiritual or religious practices
- cultural norms
- beliefs that influence understanding of illness
- coping, guilt, forgiveness
- life completion tasks

Spiritual interventions mean to explore and accept individual's spiritual practices, religious rituals if they are accepted to the patient, family and the culture and attentively listening to patient's story, individual suffering and the meaning of life to the individual and witness personally to the work of end of life.

Dignity

Preservation of dignity plays an important part in the management of terminal phase. Good death has been defined in various ways, but careful examination of what the satisfaction and psychological wellbeing in individual patient need to be identified.

There are 6 major components identified for a good death (See Box 8).

Box 8
Major components of good death

1. Pain and symptom management
2. Clear decision-making
3. Preparation for death
4. Completion
5. Contributing to others
6. Affirmation of the whole persons

Though physical symptom control is paramount in improving quality of life at the end, the latter components are mainly concentrating on completion of life and contribution to the loved once and to those who matter to that patient.

What we ultimately expect to achieve is a dignified death. To identify the exact picture of what the patient would like, there is a protocol questionnaire you could follow (See Box).

Dignity psychotherapy question protocol

- Can you tell me a little about your life history; particularly those parts you either remember most or think are the most important?
- When did you feel the most alive?
- Are there specific things you would want your family to know about you, and are there particular things you would want them to remember?
- What are the most important roles you have played in life? (e.g. family, vocational, community service)
- Why are they so important to you, and what do you think you accomplished in those roles?
- What are your most important accomplishments; what do you feel most proud of?
- Are there particular things that you feel still need to be said to your loved ones, or things that you would want to say once again?
- What are your hopes and dreams for your loved ones?
- What have you learned about life that you would want to pass along to others?
- What advice or words of guidance would you wish to pass along to your _____ (son, daughter, wife, parents, others)?
- Are there words or perhaps even instructions you would like to offer your family, in order to provide them with comfort or solace?
- In creating this permanent record, are there other things that you would like to include?

In providing dignity in death, it is important to see the patient as a whole, and the dying person would see oneself as worthy of honour

by those who cared them. It in turn will help the caregivers to prepare themselves for bereavement.

Family and care givers

Life-threatening illness in a family member is a psychological and physical stress for care givers. Common issues include anticipatory grief, anxiety and depression and empathic suffering with the distress of the patient.

> It is important to evaluate the ability of family members coping with care needs of the patient, and to identify impending breakdown in coping, role changes within the family, and financial and social needs.

The inter-disciplinary team

Specialised palliative care is a higher-standard care provided by a group of experts. An interdisciplinary team is the cornerstone in palliative care. Patient- and family-focused, coordinated care is paramount. Each team member should put their knowledge individually and collectively to a care plan.

The members of the team involved in palliative care are:

- Palliative care physician or the specialist in managing the relevant life-threatening illness
- Medical officer
- Palliative care nursing officer
- Physiotherapist
- Social worker
- Occupational therapist

- Speech pathologist
- Pharmacist
- Nutritionist
- Bereavement officer
- Spiritual care giver
- Volunteers

All members must coordinate and support the care across different settings, understanding and respecting patient's concerns. When the patient is being discharged home, the general practitioner plays a major role.

References

1. ABC Palliative care BMJ
2. Buccheri G, Ferrigno D, Tamburini M. Karnofsky and ECOG performance status scoring in lung cancer: a prospective, longitudinal study of 536 patients from a single institution. European journal of cancer. 1996 Jun 1;32(7):1135-41.
3. Crooks V, Waller S, Smith T, Hahn TJ. The use of the Karnofsky Performance Scale in determining outcomes and risk in geriatric outpatients. Journal of gerontology. 1991 Jul 1;46(4):M139-44.
4. Dignity- conserving- a new model for palliative care: helping the patient feel valued University of Ottawa by HM Chochinove 2002
5. Dignity therapy, a promising intervention in palliative care: a comprehensive literature revive https://www.ncbi.nlm.nih.gov
6. ESMO Clinical Practice Guidelines on palliative care: advanced care planning D. Schrijvers, N. I. Chernyon behalf of the ESMO Guidelines Working Group.*Annals of Oncology*, Volume 25, Issue suppl_3, September 2014, Pages iii138–iii142, https://doi.org/10.1093/annonc/mdu241
7. Ferrell BR, Temel JS, Temin S, et al. Integration of palliative care into standard oncology care: American Society of Clinical Oncology Clinical Practice Guideline Update. *Journal of Clinical Oncology* 2017; 35(1):96-112. [PubMed Abstract]
8. Hanks G, Cherny NI, Christakis NA, Kaasa S, editors. Oxford textbook of palliative medicine. Oxford university press; 2011 Jul 21.
9. Lanarkshire NH. Palliative Care Guidelines.
10. Lawton MP, Brody EM, Médecin U. Instrumental Activities of daily living (IADL).
11. Lunney,J.R., Lynn,J., and Hogan,c. (2002) Profile of older medicine descendants, Journal of the American Geriatric Society, 50,1108-1112
12. Lynn J, Adamson DM. Living well at the end of life. Adapting health care to serious chronic illness in old age. RAND CORP SANTA MONICA CA; 2003 Jan 1.
13. Medicine; volume 43:12 December2015 www.medicinelournal.co.uk

14. Medscape-Palliative Cancer Care Guidelines Updated: Aug 13, 2018; Author: Winston W Tan, MD, FACP et al
15. Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. Bmj. 2005 Apr 28;330(7498):1007-11.
16. Murray SA, Kendall M, Mitchell G, Moine S, Amblas-Novellas J, Boyd K. Palliative care from diagnosis to death. Bmj. 2017 Feb 27;356.
17. National Comprehensive Cancer Network Clinical Practice Guidelines in Oncology (NCCN Guidelines®) on Palliative Care – Version 1.2019. NCCN.org
18. NHS Northern England Clinical Network Palliative care and end of life care guidelines for Symptom control
19. Scott A Murray et al. BMJ 2017;356:bmj.j878
20. Scottish Palliative care guidelines NHS
21. Shelkey M, Wallace M. Katz index of independence in activities of daily living (ADL). International Journal of Older People Nursing. 2012;2(3):204-12.
22. State of the science of spirituality and palliative care research part 1; definitions, measurements and outcomes https://www.ncbi.nlm.nih.gov
23. Steinhauser, K et al. Ann Intern. Med. 2000. 132. 825-832.
24. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine* 2010; 363(8):733-742. [PubMed Abstract]
25. WHO 2016, Planning and implementing Palliative care services: a guide for a programme managers

Section 2

SKILLS

CHAPTER 2

Effective Communication in Palliative Care

Objectives

1. To identify the importance of communication in palliative care
2. To describe and apply key communication skills in palliative care
3. To recognise emotional reactions in patients at different stages of palliative care and implement basic interventions
4. To identify the basic aspects of communication in a family meeting
5. To identify the barriers to effective communication

> "**Effective communication itself has a therapeutic effect"**

Communication is a process that is essential for receiving and delivering information. In a medical setting, 'communication' is a primary method of obtaining information from the patients/carers and providing information about illnesses, complications and prognosis. In these types of situations, **both verbal and non-verbal** communication play important roles.

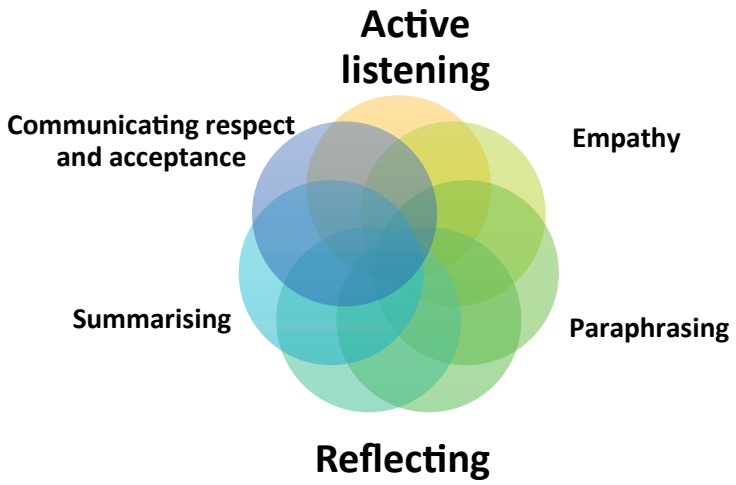
It is now widely established that effective communication leads to patient satisfaction and is related to adherence to medication and/or treatment plan (Ley, 1989). Within the broader framework of counselling, there are key communication skills that assist in making the process of palliative care more effective.

Basic skills in communication for palliative care

Active listening

Usually, listening is about hearing information. But 'active' listening is deeper and involves all our senses. In active listening you also take part in the conversation.

- This includes body language and use of voice. The body language, such as postures, gestures, movements, eye contact; using voice, stressing on words, using the right pace for your listener, pauses to mark an endpoint and beginning of another sentence, changes in pitch, intonation and rhythm help to highlight the key parts of a message to listeners.
- It is important to pay careful attention and understand the meaning of all these aspects displayed by patients, apart from listening to the words they tell you. It also improves your delivery of a message



- This improves through training – doing role plays and providing feedback by co-workers and superiors is recommended to improve active listening.

Barriers to active listening

Noise, too much technology, mispronunciation, distrust or dislike of the person, pre-conceived ideas, poor choice of words, distractions, evaluating the sender of message rather than the message itself, discomfort and inconsistency between visual, verbal and vocal aspects are known barriers. However, metacognition (the

ability to think about your thinking) may reveal to you that the main barrier is our inherent dislike to be inconvenienced. Worse, sometimes it is not fashionable to be inconvenienced. The hard working healthcare worker is sometimes looked down upon as a 'hyper-keen John'.

The on-call doctor sleeping at night would prefer to believe that the abdominal pain of a patient in the ward is not serious, rather than thinking that it might be an acute chest pain sometimes felt in epigastrium. The same can happen to a healthcare worker in palliative care, who does not want to listen to the story of the bed-ridden patient who speaks with a lot of difficulty, which might reveal the abuse she is receiving from her carers. It is inconvenient, maybe because she takes a long time and the healthcare worker has to bend down and listen carefully for many minutes; or if the abuse is detected, some action will have to be taken, which the healthcare worker finds cumbersome or even troublesome! Unless we find a way to overcome this, we will not be able to adhere to the fundamental principle in active listening.

The fundamental principle in active listening is that the patient or family member feels that we are actually listening and connecting with him or her. The best indicator of the fact that we have really understood what he/she was trying to say is our subsequent actions.

If we have really 'heard' and 'understood' what the person was trying to tell us, then we should act accordingly.

For an example, if a family member told us how difficult it is to get support from siblings in taking care of their terminally ill father, we need to practically start doing something to change that situation; we may now ask him/her how to organise a family meeting, or if we need to contact one of her siblings and discuss this. Another example is a patient trying to tell us how scared he is to die as he knows that his wife would be quite helpless without him. We may not have a fool-proof solution for this; however, we need to start thinking what we can do to address that concern.

If we do not follow up on the person's concern, all the paraphrasing and summarising will be of no use. In short, we should be actually concerned about the individual in front of us, if we are going to actively listen to him/her.

Respect and acceptance

Every human being, whether a patient or healthy person, values self-respect. Particularly for patients in a palliative care setting, it provides confidence and self-esteem.

It is essential that doctors understand that patients should be treated as individuals rather than a 'bed number' or a just a 'case'. In fact, in some instances doctors refer to patients by the bed number. This violates the principle of respect and acceptance.

It is important to refer to patients by their name, look at them while talking to them, answer all their queries, and to display a genuine interest in their condition and concerns. Addressing a patient by name is known to build good rapport.

Acceptance of patient decisions, choices and preferences might be problematic and doctors might have ethical issues of accepting some patient decisions. In these situations, it is important to provide as much information about the illness and treatment options as possible, including that of side effects and prognosis. It is also important to talk to the caregivers or guardians about these decisions.

Referring to a counsellor, psychologist, psychosocial practitioner or a psychiatrist to address any such issue that might prevent the patient getting the best care possible for themselves also needs to be considered. Doing all this takes a lot of time. And time is of

essence, particularly in busy medical settings, as well as in palliative care. However, this type of time commitment needs to be made by the doctors, if they are to uphold the principles of effective communication. The results are really rewarding.

Empathy

The word 'sympathy' derives from Greek words meaning 'with feeling'. This is most commonly used to describe the way we share someone's feelings such as sorrow or trouble. Knowing a person is sad, happy, angry, anxious or fearful and providing consoling words is known as sympathising. This is common in social encounters and medical settings. But showing empathy and displaying it through behaviour is one step further than providing just sympathy.

- The word 'empathy' means 'passion from feelings or emotion'. When you provide empathy it's about understanding the patients' emotions and making them understand that as a human being. The listener also understands what they feel and they realise why they might be feeling like that.

  Unlike in sympathy, an empathic doctor does not get emotionally unstable in the face of the emotional states of his patients.

  Once, Walt Whitman in 1855 has described well in his poem on 'Song of Myself' how we should express our empathy on a person with pain. It is as follows;

"I do not ask a wounded person how he feels. I myself become the wounded person. My hurt turns livid upon me as I lean on a cane and observe"
(https://www.grammarly.com/blog/empathy-sympathy/).

The best way to learn empathy is by working with disabled people such as the blind.

At times, when a patient is emotionally overwhelmed, we try to tell them how 'we' dealt with a similar situation or how 'someone' else we know dealt with such emotions.

We all have our unique ways of dealing with emotions and especially in a setting like palliative care, sensitive issues such as a person's health, illness and death cannot be equated to another although there could some universal similarities like crying, being angry or avoidance.

Hence, it is important to avoid sharing our personal stories with patients.

Paraphrasing

Paraphrasing is re-telling the patient what he told you.

- This is a skill that is very important in medical settings, as it helps the listener/doctor to clarify what the patient has uttered.

- It makes the patient feel understood and cared for. This avoids miscommunication in understanding which has a lot of impact on treatment plans or decisional choices. For example, if you can repeat back a certain symptom like diarrhoea or constipation in simple but with clear wording, you will have a chance to determine complications, side effects of drugs or any other issue that is related to their health status at this palliative care stage. To do this, you have to listen actively!
- At a more advanced stage of this practice, the doctor could paraphrase the patient's fears about death and pain. Such paraphrasing by the doctor helps the patient 'hear' his own worries from another person. This could help him to put things in perspective and soothe his mind. In order to do that well, you may have to deal with your own fears about death, dying and pain.

Summarising

This is usually done at the end of a discussion of treatment options/introducing new treatment/discarding/optimising existing medication, or at the end of a disclosure of serious news about their medical condition.

- Summarising serves the purpose of avoiding miscommunication, misunderstanding and allows patients to ask for clarifications.
- It is also good practice for doctors to gather all the important information about the patient and the condition and repeating it all as a summary, so that they take away the most important things that need following-up or to make an informed decision.
- At times, doctors assume that patients would remember all what they say. But this is not so, particularly as human memory is very vulnerable. This vulnerability becomes further intensified when a person is seriously ill and/or when doctors use medical terms.
- Hence, summarising is extremely important, though it does take extra time to do so.

Reflective practice

Reflective practice is one of the most important parts of the communication process and it allows the personal development of the doctor. This aspect does not involve the patient.

- Instead, after summarising and the patient has left the discussion setting, it is the time to 'look back' on your

utterances, patients' responses and overall communication process.

- These reflections should be made into brief notes which will help the doctor to use at their clinical meetings and to obtain feedback from co-workers and superiors on the practice of communication skills.
- In some medical settings in Sri Lanka, it is not the practice to have such meetings to reflect on a doctors' practice of communication as yet. If so, it is important to establish such a practice as its benefits are significant for both patient and doctor.
- For, in the case of the doctor, it serves the important purpose of 'unloading' the emotional significance of working in a palliative care setting, as working in such settings could become an emotional burden on health practitioners.
- This kind of reflection reduces and prevents burn-out.

Barriers to effective communication

There can be several factors that can reduce the effectiveness of communication between the patient and the doctor. See Box 1

Box 1

- Language, culture, age, gender and illness status of the patient
- Culture-specific beliefs, practices, values about health, illness and death
- The use of medical jargon
- Feelings and emotions of the burden of responsibility
- Doctor's lack of attention and interest
- Distractions in the healthcare setting (such a constant telephone calls)
- Discomfort in disclosing serious/sensitive information
- Self-esteem issues and lowered confidence to be effective in a palliative care setting
- Personal psychological stress, anxiety, and/or fear of negative evaluation by others
- Lack of feedback on the doctors' communication skills
- Diversity in the multidisciplinary health team
- NB: Also read "Barriers to active listening" above.

Anxiety evoking feelings:

Patients can express feelings that doctors find hard to manage; for instance, a patient who is very depressed or scared to die. Doctors may feel threatened by feelings directed towards them, for instance hostility or liking. Alternatively, helper anxiety may be evoked by the intensity of patients' feelings about others, for instance grief over bereavement.

Anxiety-evoking patients:

Doctors may find themselves feeling threatened by certain categories of patients; for example, patients of the opposite sex, seriously disturbed patients, highly successful patients, very intelligent patients, and patients who hold strong feelings with which the doctor disagrees.

Being prejudiced:

Doctors are not immune to varying degrees of prejudice. For reasons connected with your upbringing, you may tune-out with people different to you because of their age, sexual preference, culture, race, social class, physical disability or level of intelligence.

Being preoccupied with oneself:

Being preoccupied with your own affairs can interfere with the patient's accessibility to you. For instance, if you have just come from a heated meeting, you may be less ready to listen carefully to your patient. If you have just rushed through heavy traffic to

get to the clinic, you may not listen attentively until you have calmed down.

You may think about something said in an earlier session and fail to attend to the present. In addition, you may have intrusive personal worries that hamper your effectiveness as a good listener.

Presenting a professional façade:

Genuineness is an important characteristic for a doctor. A difference exists between being genuine and 'seeming-to-be-genuine'. Some doctors are too concerned with maintaining a smooth professional façade. Their concern with how patients perceive them may interfere with being receptive to their patients accurately. Such doctors are too busy listening to their own needs to accommodate patients fully. Maintaining a professional façade is especially difficult when patients challenge your professional adequacy directly.

Emotional exhaustion and 'burn out':

Doctors often face a combination of difficult environments, demanding patients and poor skills that set limits on their involvement. 'Burn out' is exhausting one's physical and mental resources. It is to wear oneself out by excessively striving to reach some unrealistic expectation imposed on oneself, by the values of society or by oneself. Emotionally exhausted doctors

may be less accepting of patients than when they feel well. Their energy level and sense of personal accomplishment is low. Helping relationships, instead of being positive challenges, can become endurance tests for the doctor.

Insufficient administrative support:

In this situation, doctors may spend much time securing budgets and dealing with other administrative matters. Frequently, they lack adequate secretarial support. Insufficient administrative support can undermine morale, increase caseloads and involve doctors in routine secretarial and administrative chores obviously decreasing their efficiency.

Physical barriers:

Physical barriers may contribute to your being less accepting of patients. For example, you may be too hot, you may lack privacy, your room may be cheerless, your chair may be uncomfortable, the lighting may be poor or there may be too much noise. These physical discomforts may prevent you from paying attention to your patients effectively.

Lack of assertiveness:

If the doctor/health care worker lacks the ability to be bold enough to do the right thin as perceived is said to have no backbone and lack assertiveness. Then this person does what the others want him/her to do, and thus may fail to

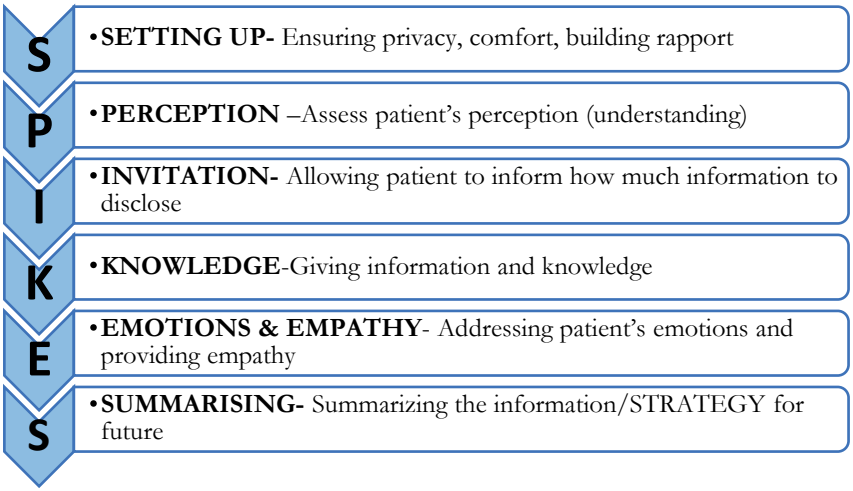
communicate correctly and to make difficult decision that are needed.

When the SPIKES model is followed, then assessing the person's emotions, feelings and other factors will provide ways to avoid these barriers. Further, senior doctors could facilitate the establishment of good practices in effective communication skills in their teams. This could alleviate most of the barriers indicated above.

Giving serious information ('breaking bad news')

Breaking serious news frequently creates a tense and distressing experience for the patient as well as to the doctor. As pointed out by Buckman (2005), "*any news that adversely and seriously affects individual's view of his or her future*" can be defined as a 'bad news'. Therefore, there are adverse consequences for the patients and their families in such situations.

Disclosing serious/bad news (Using SPIKES model for communication),



(Baile et al 2005)

The above mentioned SPIKES protocol is not a script, but it is a good strategy to use for breaking bad news. This protocol highlights the most important features of a bad news interview, methods of assessing the situation and how to respond constructively to what happens.

- In the first step 'Setting': where to break bad news, whether to have relatives, physical contact of interview, introducing yourself and listening skills are very important.
- In the step of Perception, it is important to know what the patient or family already know about the patient's medical

condition. It is not suitable to confront their denials at this stage.

- Whether the patient or the family wishes to know the details of the medical condition and treatment is very important in the step of Invitation.
- In the step of giving information and Knowledge, it is critical to check if the receiver of the news still wants you to go on and tell more. Sometimes, some people do not want to know everything. They might indicate you to stop. Other important aspects here are using a language intelligible to patient, considering their socio-cultural background, educational level and current emotional state. In addition, checking whether patient or family understand what you said, responding to their reactions as they occur, giving any positive aspects first and giving accurate facts about treatment options, prognosis and costs etc. are also very significant in this step.
- In the step of expressing Emotions and empathy, identification of emotions and cause or source of emotion is very important. Also, it is not necessary for you to feel the same emotion or agree to patient's or family member' viewpoint.
- Closing the interview, asking whether they want to ask questions for further clarification and offering agenda for

the next meeting etc. are significant in the last step of this SPIKES protocol.

By breaking serious news using above steps, we can gain different benefits such as reducing stress in doctors, better psychological adjustment for the patients, facilitating open discussion among patients, family members and doctors. Also, there are some pitfalls in breaking serious/bad news such as inadequate time/information, not allowing time for responses, allowing denial to remain, failure to elicit patient's understanding of situation, giving false reassurances about the future and removing all hope. However, the SPIKES protocol provides clear steps to follow and we can practice them until we feel more comfortable breaking bad news.

Communicating with the family (family meeting)

In caring for a patient, his/her family plays a very significant role. Therefore, family participation in deciding the treatment plan, future care of the patient, informing the symptoms of the illness, side effects of the drugs are very important. The following steps can be used in conducting such a family meeting:

- Set clear objectives; prepare an agenda for the meeting
- Arrange the location in advance and inform all persons
- Make sure you are not disturbed
- Be on time, be prepared and stay focused

- Assure participation of all participants and know who they are
- Assure accurate notes/recording
- End the meeting with a summary

In the disclosure of serious news about a patient's illness and treatment to the family, doctors can use the above-indicated SPIKES model too.

Summary:

Communication is a two-way process where both obtaining and providing information should equate. Speaking, listening and observing are important in this communication process. It is led by the patient and the practitioner, and involves skills such as using the right words, active listening, empathy, respect and acceptance, summarising and reflecting. Health professionals can use the SPIKES model to disclose serious information about a medical condition. This process provides health professionals a framework to communicate about the serious news and to ease the patient's distress to cope with his life limiting/terminal illness. It is also important to acknowledge and address barriers to effective communication such as language issues, cultural practices, illness status of a patient, and practitioner competence.

References:

1. Baile, W.F., Buckman, R., Lenzi, R., Glober, G., Beale, E.A., Kudelka, A.P. (2000) SPIKES – A Six Step Protocol for Delivering Bad News: Application to the Patient with Cancer. Oncologist, 5:302-311
2. Buckman, Robert A. (2005). "Breaking Bad News: the S-P-I-K-E-S Strategy". *Community Oncology*. March/April 2005.
3. Dunne, K. (2005). "Effective communication in palliative care". *Nursing Standard*. 20, 13, 57-64.
3. Hall, S. & Payne, S. (2010). Palliative and end-of-life care. In D. French, K. Vedhara, A. A. Kaptein, and Weinman, J. (Eds). *Health psychology (2nd ed.) (pp. 398-409). Wiley; Essex, England*
   Hatfield and Harriet P. Lefley Ed., *Families of the Mentally Ill: Coping and Adaptation*. New York, London: The Guilford Press.
4. Hatfield, A. B. (1987). "Families as Caregivers: A Historical Perspective". In, Agnes B.
4. https://www.grammarly.com/blog/empathy-sympathy/
5. Lunenburg, Fred C. (2010). "Communication: The Process, Barriers and Improving Effectiveness". *Schooling*. Vol.1, No.1. 2010:1-11: Sam Houston State University.
6. Schultz, E. (2017. *Palliative care: Communication, Clinical Adviser* http://www.clinicaladvisor.com/hospital-medicine/palliative-care-communication/article/603730/

CHAPTER 3

Team-Building in Palliative Care

Teamwork is a joint action by two or more people, in which each person contributes with different skills and expresses his or her individual interests and opinions to the unity and efficiency of the group in order to achieve common goals.

Palliative care depends heavily on a multiple spectrum of disciplines, knowledge, and skills. Therefore, teamwork is an integral part of the of palliative care service.

Multi-disciplinary and cross-functional, interdisciplinary teams offer benefits to patients, practitioners and specialist areas of care. Such teams harness the skills required for the task and combine them in a distinctive way, which cannot be achieved individually.

This has a number of advantages:

- An increased range of services at a single consultation
- The workload is easier to manage
- Collegiate support
- Cross-fertilisation of ideas
- A more holistic approach

Identifying the leadership of teams can be difficult. In Sri Lankan hospital settings in a non-cancer palliative care teams, usually a physician will be taking the leadership of the team. An oncologist will be the leader for a patient with cancer. However, the primary clinician responsible for the patient will play the leadership role for a specific patient, depending on the clinical situation.

The hospital palliative care team may include specialists, non-specialist doctors, nurses, allied health practitioners (physiotherapists, occupational therapists and speech therapists), counsellors, pharmacists and social workers. There can be other members depending on the patient's requirement and the human resources available at the hospital.

The hospital palliative care team should always communicate and accommodate community partners (government or non-governmental). General Practitioner/primary care doctor of the patient's locality would play an important role, especially in coordinating home care and the hospital care. Community nurses and public health midwives working in primary healthcare could be guided to provide palliative care services to patients and the families of their area. Community partners would also include welfare officers, religious leaders and the volunteers.

Teams are complex structures, in terms of membership structure, operations and institutional culture. According to 'Plant's Iceberg

Model' (see *Figure 1*) the processes and methods by which an organisation operates are the 'visible' part of teamwork, and the factors which can influence change and organisational development are submerged. Thus issues relating to teamwork that lie in the submerged iceberg should be considered and assessed in optimising a palliative care team function.

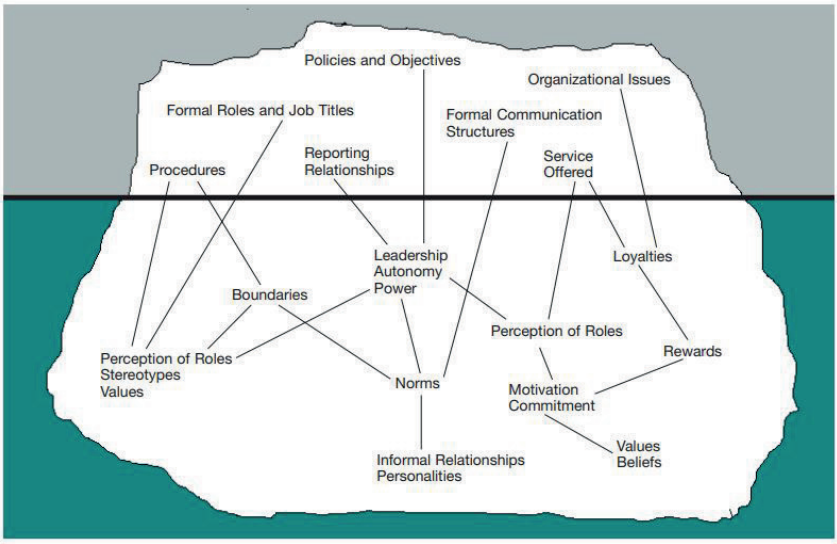


Figure 1: Plant's Iceberg Model of teamwork (1987).

For a team to function effectively, the members must have a common purpose, an understanding of each other's role and an

ability to pool resources. Regular and professional communication among team members are the most important factors for the team to be successful. Therefore, regular meetings and case conferences are a must for the proper functioning of a palliative care team.

There is a place for interaction of different clinical teams in patient care, i.e.; interdisciplinary interactions. E.g. Palliative care team with the oncology or neurology teams.

Patient identification and trigger system: The palliative care team should have a patient identification system. It may be through an awareness program of healthcare workers and communication with treating clinicians. With time, a team can develop a checklist to identify the probable patients needing palliative care. Final decision-making should be a joint decision with the treating clinicians, family and the patients. The patient is always the final decision-maker if there is capacity to participate.

Dispute of leadership, personal disputes among members and poor communication leading to different opinions and conclusions are the most common causes for failure of a palliative care team. Regular meetings and case discussions are the best method to avoid these issues.

Key practice points

- Palliative care requires multitude of skills and knowledge
- Multidisciplinary and interdisciplinary team interactions are required
- Team members should work for a common goal to manage patient as a whole
- Palliative care team should interact with the community.
- Final decision making is always with the patient.

References

1. Crawford GB, Price SD. Team working: palliative care as a model of interdisciplinary practice. The Medical Journal of Australia. 2003 Sep 15; 179(6):S32.
2. Hill, A. (1998). *Multiprofessional teamwork in hospital palliative care teams. International Journal of Palliative Nursing, 4(5), 214–221.* doi:10.12968/ijpn.1998.4.5.9099
3. Ovretveit J (1995) Team decision making. J Interprofessional Care 9(1): 41–51
4. Plant R (1987) Managing Change and Making it Stick. Gower, Aldershot
5. Rock, W. (2003). Interdisciplinary teamwork in palliative care and hospice settings. American Journal of Hospice and Palliative Medicine®, 20(5), 331–333. doi:10.1177/104990910302000502
6. Shaw J, Kearney C, Glenns B, McKay S. Interprofessional team building in the palliative home care setting: Use of a conceptual framework to inform a pilot evaluation. Journal of interprofessional care. 2016 Mar 3;30(2):262-4.

CHAPTER 4

Record Keeping in Palliative Care

Record keeping is an important aspect of patient management in any branch of clinical medicine. The primary objectives of record keeping in palliative care are to keep track of the delivery of standard care, clinical decision making, for continuity of care and for communication between the healthcare team members. When properly and truthfully documented, medical records carry the best evidence for the quality of care, thus are sources for transparency of delivered care and quality assurance and for clinical audits. In addition, they provide a good source for scientific research.

Research has shown that multidisciplinary documentation benefits both patients and staff. It reduces duplication, saves time, improves clarity of information and finally improves teamwork. Thus, maintaining records that are contributed by the entire team is imperative in continuing holistic care to the patients.

Palliative care record could be paper-based or electronic. Electronic medical records (EMR) have become popular in record keeping recently. A few government hospitals in Sri Lanka also maintain EMRs.

Record keeping practice principles

It is advisable to follow the following principles in record keeping.

- To have a structured format which is user friendly.
- To have clearly written records of the decisions made about a person's treatment and care and who was consulted in relation to those decisions.
- To document all consultations, especially the opinion of the palliative care team responsible for delivering care to a particular patient, the decisions and clear goals and the agreed care plan.
- Ensure that the agreed care plan is shared among all involved in providing the patient care, including both paid and unpaid caregivers outside the team and other health professionals involved in providing the person's care. This is mainly important when people move across different care settings (hospital, ambulance, and hospice) and during any out-of-hours period. Failure to communicate relevant information can lead to inappropriate treatment and failure to meet the patients' needs.

- Check the handover arrangements where you work, and use the available records and arrangements for information storage and exchange.

Core content of a Palliative Care Record

Record keeping could be done in different ways in different formats.

1. Person demographics
    - Person name including preferred name
    - Gender
    - An Identifying No. (BHT No., Clinic No., Serial No.: whichever relevant)
    - Date of birth
    - Postal Address
    - Contact numbers
2. Main care giver's name and contact details
3. Name and contacts of the GP/primary care physician/hospital
4. Medical history
5. Likely prognosis
6. Patient's understanding of medical condition
7. Current medications and medical devices: regular and PRN
8. Allergies and adverse reactions
9. Family medical history (if relevant)

10. Social history

    Family members, who lives at home, relevant family dynamics, type of accommodation, home assistant services provided, employment issues, financial issues, alcohol and smoking history etc.

11. Spirituality: religious or otherwise, values
12. Patient's and caregivers' concerns, expectations and wishes
    - Caregivers' concerns
    - Anticipatory care plan
    - End of Life Care Plan (e.g., where and how the patient/family wishes the patient to be cared for as they deteriorate, and during their terminal phase)
13. Current issues (consider both patient and the family/caregivers)
    - Physical: physical symptoms, oral intake, bowel and bladder function, physical function including current equipment in home and what is still needed, nutritional assessment
    - Psychological state
    - Social issues
    - Spiritual issues
14. Examination Findings
    - Observations

- Level of consciousness, general examination, oral cavity, cardiovascular system, respiratory, abdominal and peripheral examinations and pressure area assessment
- Other relevant assessment: neurological examination, functional assessment, cognitive assessment

15. Clinical impressions

    Summary of significant assessment findings, problems and any diagnoses made
16. Discussions: relevant discussions/explanations/decisions made with patient/family
17. Management plan of the multidisciplinary team

Anticipatory Care Plan and Advance Directives

Anticipatory Care Plan (ACP), which is also known as Advance Care Plan, is a voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future. The goal of ACP is to ensure that such patients receive medical care that is consistent with their preferences. If patients wish, their choices or decisions relating to care and treatment could be recorded, which can then be referred to by their carers (whether professional or family carers) in the event

that they lose capacity to decide once their illness progresses. Such recorded specific medical treatment decisions are known as advance directive (AD). ACP may include the completion of an AD, although this is not the primary intent of ACP discussions. The main objective of ACP is to ensure that patients receive care that is aligned with their goals and values.

An ACP will be important to document, as it could be useful in future management of a palliative patient. It could contain individual's desire for treatments such as analgesia, hydration, feeding, use of ventilators and CPR. ACP could be changed or updated at patient's request or if palliative care team feels that there are reasons to reconsider them. Patient's GP could be a good resource in preparing ACP as patient and the family have a close relationship with their family doctor, where he also could contribute positively to the discussion.

Living will is a type of advance directive. This written document outlines patient's healthcare wishes for end-of-life care if the patient become terminally ill and cannot make decisions on his or her own.

ACP/AD and the living will are not yet legally recognised in Sri Lanka.

References:

1. Acevedo, J. Documentation & Coding Handbook: Palliative Care. California Healthcare Foundation. 2019.
2. Bok S. Personal directions for care at the end of life. New England journal of medicine. 1976 Aug 12;295(7):367-9.
3. Doody O, Bailey ME, Moran S, Stewart K. Nursing documentation in palliative care: an integrative review.
4. Gunhardsson I, Svensson A, Berterö C. Documentation in palliative care: nursing documentation in a palliative care unit—a pilot study. American Journal of Hospice and Palliative Medicine®. 2008 Feb;25(1):45-51.
5. Palliative care co-ordination: core content Record keeping guidance. National End of Life Care Intelligence Network. NHS, UK. 2015.
6. Simpson M. Multidisciplinary patient records in a palliative care setting. nursing times. 2003 Jan 1;99(3):33-4.
7. Sudore RL, Lum HD, You JJ, Hanson LC, Meier DE, Pantilat SZ, Matlock DD, Rietjens JA, Korfage IJ, Ritchie CS, Kutner JS. Defining advance care planning for adults: a consensus definition from a multidisciplinary Delphi panel. Journal of pain and symptom management. 2017 May 1;53(5):821-32.
8. Website: http://advancecareplan.org.uk
9. Zegers M, de Bruijne MC, Spreeuwenberg P, Wagner C, Groenewegen PP, van der Wal G. Quality of patient record keeping: an indicator of the quality of care? BMJ quality & safety. 2011 Apr 1;20(4):314-8.

- **Authors wish to thank Dr Amanda Fernando, Palliative Care Specialist in Australia and Dr Libby Sallnow, Palliative Care Specialist in UK for helping out in compiling this chapter.**

Section 3

SYMPTOM CONTORL

CHAPTER 5

Pain

Introduction

The International Association for the Study of Pain (IASP) defines pain as 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage'. Pain is one of the most distressing symptoms in palliative care patients of malignant and non-malignant pathology, and proactive identification and treatment can benefit patients in both short- and long-term outcomes. As such, clinicians at all levels should be equipped to appropriately assess and provide a suitable management plan for patients suffering due to palliative diagnosis.

Non-pharmacological pain management is often missed by both patients and clinicians, due to inaccessibility and unawareness. Pharmacological undertreatment also occurs, owing to such patient factors as undue fear of adverse effects of pain medications, including addiction and tolerance. This is equally affected by clinician-related factors, such as lack of pain assessment and management skills, concerns regarding adverse effects. As a result, poorly controlled pain reduces quality of life and functional status,

while worsening mental comorbidities such as anxiety and depression.

Pain assessment

The gold standard of pain assessment is a patient's own description, as pain is a subjective experience. Individual pain perception is moulded by a number of variables See box below

- Physicality (fatigue, existing chronic pain),
- Psychological state (anxiety, anger, depression, past experience and/or trauma),
- Social and familial responsibilities
- Various spiritual and cultural confounding factors.

Pain history

Multiple factors can influence pain history. These may include stigmata around pain medication, previous adverse effects related to medications, the desire not to divert clinicians' focus on disease-specific treatments, and intention to please clinicians. Likewise,

clinicians need to consider and improve the cultural and language barriers during assessment of pain history.

When performing a basic pain assessment, clinicians must consider a number of parameters covering:

- Site of pain
- Timing, onset and duration of pain
- Quality and severity of pain
- Precipitation or relieving factors
- Radiation
- Associated symptoms (e.g., nausea).

An array of well-validated tools are typically used to assess pain severity, depending on age group and cognitive function (e.g., when dealing with patients with dementia or delirium, or treating children). This includes a number of numerical scales, descriptive scales (e.g., Wong–Baker Faces Pain Scale; see Fig. 1) and observatory assessments, particularly when dealing with patients with cognitive impairment (e.g., Abbey pain scale, see Fig. 2). Essentially, pain assessment should be a dynamic process to reassess and titrate pain management.

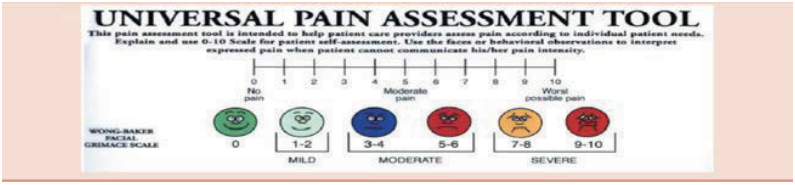
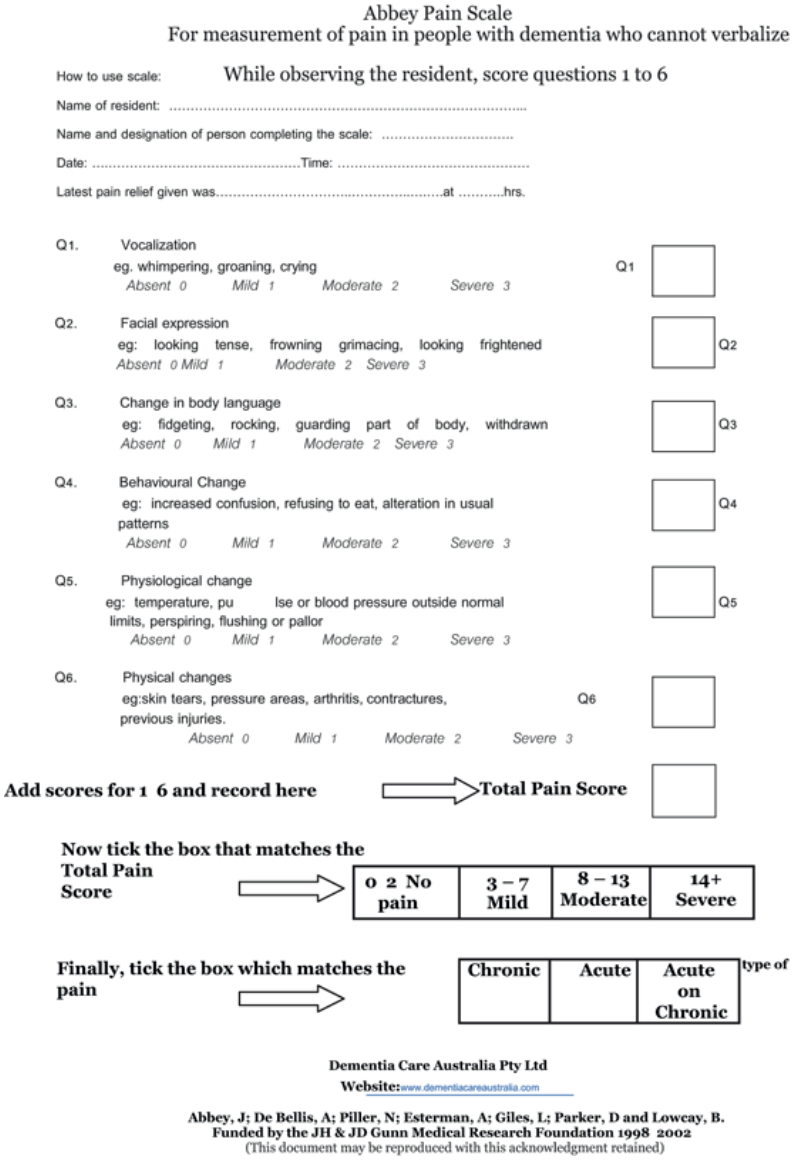


Figure 1. Wong–Baker Faces Pain Scale


Abbey Pain Scale
For measurement of pain in people with dementia who cannot verbalize

How to use scale: While observing the resident, score questions 1 to 6

Name of resident: .....

Name and designation of person completing the scale: .....

Date: .....Time: .....

Latest pain relief given was.....at .....hrs.

Q1. Vocalization
eg. whimpering, groaning, crying
Absent 0 Mild 1 Moderate 2 Severe 3
Q1

Q2. Facial expression
eg: looking tense, frowning grimacing, looking frightened
Absent 0 Mild 1 Moderate 2 Severe 3
Q2

Q3. Change in body language
eg: fidgeting, rocking, guarding part of body, withdrawn
Absent 0 Mild 1 Moderate 2 Severe 3
Q3

Q4. Behavioural Change
eg: increased confusion, refusing to eat, alteration in usual patterns
Absent 0 Mild 1 Moderate 2 Severe 3
Q4

Q5. Physiological change
eg: temperature, pu lse or blood pressure outside normal limits, perspiring, flushing or pallor
Absent 0 Mild 1 Moderate 2 Severe 3
Q5

Q6. Physical changes
eg:skin tears, pressure areas, arthritis, contractures, previous injuries.
Absent 0 Mild 1 Moderate 2 Severe 3
Q6

Add scores for 1 6 and record here ⇒ Total Pain Score

Now tick the box that matches the Total Pain Score ⇒

0 2 No pain	3 – 7 Mild	8 – 13 Moderate	14+ Severe

Finally, tick the box which matches the pain type of pain ⇒

Chronic	Acute	Acute on Chronic

Dementia Care Australia Pty Ltd
Website: www.dementiacareaustralia.com

Abbey, J; De Bellis, A; Piller, N; Esterman, A; Giles, L; Parker, D and Lowcay, B.
Funded by the JH & JD Gunn Medical Research Foundation 1998 2002
(This document may be reproduced with this acknowledgment retained)

Figure 2. Abbey pain scale.

Types of pain

Despite having mixed pathology in most pain syndromes, clinicians need to become familiar with pain characterisation to understand the pathology, tailor the management options and communicate with other professionals. Table 1 provides an example of how pain is clinically categorised for practical management, and Table 2 captures the need for clinicians to become familiar with the patterns of pain exacerbation in view of optimising pain management strategies.

Table 1. Categorisation of pain for management

Type of pain	Subtype of pain	Pathology	Pain characteristics
Nociceptive: relates to stimulation of nerve endings (nociceptors) due to noxious stimuli	Somatic	Superficial: skin and subcutaneous tissue involvement	Superficial: hot or sharp pain
		Deep: bone, joint, muscle and tendon involvement	Deep: aching or throbbing pain
	Visceral	Solid or hollow organ involvement	Dull, pressure, tightness or

		crampy pain
Neuropathic: relates to nerve damage	Nerve damage related to malignant or non-malignant pathology or its treatment	Burning, tingling, stabbing or electric shock-like pain

Table 2. Patterns of pain exacerbation for pain management

Type of pain	Description	Clinical features
Breakthrough pain	Pain occurs due to natural fluctuation of pain or inadequate background pain control	Signs suggestive of inadequate background pain control Lack of predictability
Incident pain	Pain exacerbated by predictable triggers	Pain exacerbated by limb movement or pain related to wound dressing

Physical examination

While focused physical examination followed by a systematic review is important to understand the pathophysiology of pain, it is also important that clinicians assess:

- Functional impairment due to pain
- Non-verbal clues and pain behaviour
- Signs of pain sensitisation
- Adverse effects of pain medications.

Examination findings provide crucial information on pain assessment, especially when dealing with patients who have impaired verbal communication skills due to cognitive disability, impaired consciousness or terminal stage.

Investigations

A thorough history and physical examination should guide essential investigations. However, this should only be ordered if management decisions alter.

Pain management

One key tool for managing pain is the World Health Organization's 'analgesic' or 'pain relief ladder' (Fig. 3). Although it was developed for cancer pain relief, it is widely used in non-cancer pain management around the world.

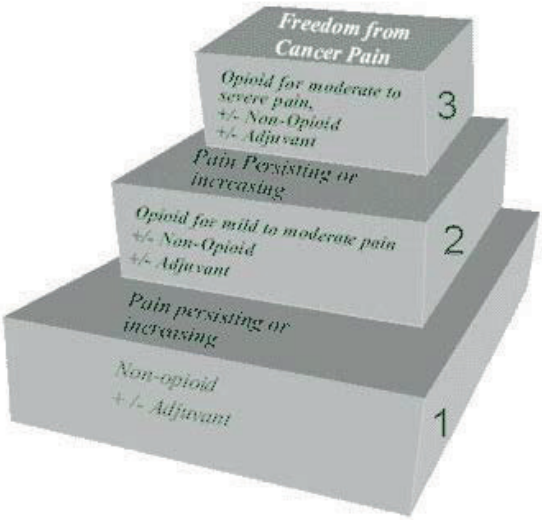


Figure 3. World Health Organization 'analgesic' or 'pain relief' ladder.

Pharmacological management

Opioids

Opioids are considered the mainstay of pain management in malignant palliative care settings. Increasing evidence suggests that opioid preparations are effective in alleviating pain and shortness of breath in non-malignant palliative care, including (but not limited to) neurological, respiratory, nephrological and cardiac pathologies.

The choice of opioid is decided on both medical and practical grounds. This includes clinicians' familiarity with opioid use, availability, patients' adverse effect profile, patients' existing comorbidities, and predicted medication compliance.

Importantly, opioid combinations are not recommended for palliative care due to possible pharmacokinetic complications. Exceptions are made if both immediate-release and slow-release preparations are not available in the same opioid.

Opioid adverse effects

Patients will develop tolerance towards most opioid-related adverse effects. Discussion and reassurance on possible short-term adverse effects may improve long-term adherence to medication. Constipation is most likely the only long-term side effect, needing

proactive and ongoing clinical input. Table 3 outlines the type and duration of common adverse effects associated with opioid treatment.

Table 3. Adverse effects and duration of opioid treatment

Adverse effect	Duration of adverse effect (when dose stabilised)
Sedation	2–3 days
Nausea/vomiting	7–10 days
Pruritus	7–10 days
Constipation	Always a problem. Does not go away after few days.
Respiratory depression	Extremely rare with appropriate opioid use

Opioid addiction is a common concern for patients, their families and for clinicians, reflected as a barrier to effective pain management. Risk of addiction is rare during pain management in a palliative care setting. If clinicians have high suspicion of addictive behaviour, they are encouraged to discuss this with the relevant specialists before prescription.

Opioid toxicity-related respiratory depression is rare when setting the appropriate opioid treatment. Clinical vigilance is necessary if rapid opioid dose escalation occurs or if multiple prescribers are involved. Opioid medication combinations are often discouraged in palliative care practice except in some highly specialised settings.

When beginning treatment on an opioid-naïve patient, clinicians must prescribe 2.5–5 mg (oral) morphine 4-hourly when needed; the oral dosage effect will start in 20-30 minutes and lasts between 4–6 hours. If a patient is severely distressed and needs rapid onset of action in an inpatient setting, use 2.5–5 mg (subcutaneous) morphine 4-hourly when needed. Clinicians must then calculate total daily (24-hour) pro re nata (PRN) requirement of opioids over the following days. Patients can then be started on an equivalent dose of slow-release opioid to match daily requirement. Further titration of slow-release opioid medication is done based on ongoing PRN requirements. Fig. 4 provides an example of a recommended opioid treatment plan.

For titration of opioids on a patient with a background of opioid use:

- Calculate the daily oral morphine equivalent dose depending of existing slow-release opioid; patients should

use one-sixth of their daily requirement as a breakthrough (PRN) requirement

- Calculate the daily PRN requirement over the next few days
- Escalate the slow-release opioid to the total of existing slow-release opioid and the daily PRN requirement.

- Fentanyl 50 microg/hr patch = (oral) morphine 120 mg per day
- Breakthrough dose: (oral) morphine 20 mg or (subcutaneous) morphine 10 mg 4-hourly PRN
- Patient needed extra 3 breakthrough doses of (oral) morphine 20 mg to adequately control pain
- Patient's total daily opioid use: 120 mg + 60 mg = 180 mg
- Above dose is equivalent to Fentanyl 75 microg/hr patch
- Patient's new breakthrough dose: 180/6 = 30 mg
- (Oral) morphine 30 mg or (subcutaneous) morphine 15 mg 4-hourly PRN

Figure. 4. Example of an opioid treatment plan

Weak opioids

Codeine

(Oral) morphine 10 mg = (oral) codeine 80 mg
Available preparations: • Oral immediate release: paracetamol 500 mg + codeine 8 mg tablets, paracetamol 500 mg + codeine 30 mg tablets

Use

- Codeine is rarely initiated in specialised palliative care practice due to pharmacokinetic and pharmacodynamic limitations in palliative care practice.
- Codeine is used only if a patient's pain is stable on current pain regimen containing codeine; clinicians can continue current dose.

Benefits

- Codeine is readily available.
- There is less stigma among clinicians and patients regarding its use.

Concerns

- Codeine is mostly available in fixed-dose combinations with other medications (e.g., paracetamol + codeine).
- Side effects include higher incidence of constipation.
- Codeine needs to convert to its active metabolites to be effective in pain management. Genetically, some patients do not have the capacity to convert codeine in this manner.

Tramadol

(Oral) Tramadol 50 mg = (oral) morphine 10 mg

Available preparations:

- Oral immediate release
- Oral slow release

Use

- Effective at early stages of cancer diagnosis. However, tramadol use in palliative care is restricted due its adverse effect profile.

Dose (Oral)

- Tramadol 50 mg 8-hourly up to 100 mg 8-hourly

Benefits

- Tramadol is widely available.

Concerns

- Adverse effect profile includes potential serotonergic syndrome.
- Tramadol requires multiple drug interactions.

Strong opioids

Morphine

(Oral) morphine 30 mg = (intravenous/subcutaneous) morphine 10 mg

Available preparations:

- Oral immediate release: 10 mg, 15 mg, 30 mg tablets, 2 mg/ml syrup
- Oral slow release: 10 mg, 15 mg, 30 mg tablets
- Injectable: 15 mg/ml

Use

- Morphine is considered as the prototypical opioid in pain management in palliative care.
- Immediate release (oral) morphine has onset of action in 20–30 minutes and duration of action up to 4–6 hours.
- Morphine has an oral bioavailability of 30–35% (hence, [oral] morphine 30 mg = [intravenous/subcutaneous] morphine 15 mg).

Benefits

- Most clinicians are familiar with morphine use.
- Morphine is the most widely available strong opioid (in a wide range of preparations).
- Morphine is the only injectable strong opioid readily available for use in palliative care.
- There is no theoretical ceiling dose, if escalated appropriately.

Concerns

- Adverse effects relate to accumulation of active metabolites in renal failure.
- There is noted community stigma around morphine use.

Fentanyl

(Topical) Fentanyl patch 25 μg/hour = (oral) morphine 60 mg per day

Available preparations:

- Transdermal patch: 50 μg/hour
- Injectable: 100 μg/2 ml injection, 500 μg/10 ml injection

Use

- Fentanyl is commonly used in transdermal patch form for palliative care use. Injectable preparations are widely used in perioperative pain management.

Benefits

- Transdermal patches are useful for patients who cannot be started on oral opioids.
- Fentanyl has no active metabolites (safe in renal failure).
- There are only minimal neurocognitive adverse effects reported with Fentanyl use.
- Fentanyl has less reported incidence of constipation compared to other opioids.

Concerns

- Limited number of dosages is available. (Cutting the transdermal patches to achieve desirable dose is controversial.)
- Fentanyl is not suitable when rapid escalation of pain management is necessary, as transdermal patches can take more than 12 hours to deliver a desirable dose.
- Patients need to have a substantial amount of adipose tissue for transdermal patch absorption.
- Absorption can vary depending on environmental temperature.
- Some patients can experience end-of-dose failure after 28 hours of patch application.

Methadone

(Oral) morphine 10 mg = variable
Available preparations: • Only used in specialised palliative care practice

Use

- Methadone is a highly specialised medication used only by palliative care specialists, pain medicine specialists and

addiction medicine specialists. Non-specialised medical staff should not be involved in dose titration of methadone.

Neuropathic pain medication

Anti-epileptic medications

Most anti-epileptics used in pain management alter the calcium influx into neurones, resulting in reduction of synaptic glutamine, norepinephrine and substance P.

Recommended doses

- (Oral) gabapentin 300 mg daily (titrated weekly up to a maximum daily dose of 2,400 mg per day in divided doses).
- (Oral) pregabalin 75 mg daily (titrated weekly up to a maximum daily dose of 300 mg twice a day).
- (Oral) sodium valproate 200 mg daily (titrated every third day up to a maximum daily dose of 1000 mg per day in divided doses).
- (Oral) clonazepam 0.5 mg daily (up to a maximum daily dose of 2 mg twice a day).

- *Use with caution*:
- (Oral) carbamazepine 100 mg twice daily (titrated every third day up to a maximum daily dose of 400 mg twice a day).

Antidepressant medication

Antidepressants exert pain relief properties independent of their antidepressant effects. They should be first-line medications if patients display coexisting depression; however, patients should be warned about the class-specific (tricyclic antidepressants/serotonin–norepinephrine reuptake inhibitors) adverse effects. Antidepressants are widely used in non-malignant neuropathic pain control including diabetic neuropathy, post-herpetic neuralgia and post-stroke pain syndromes.

Recommended doses

- (Oral) amitriptyline 10–25 mg at night (titrated weekly up to a maximum daily dose of 75 mg at night).
- (Oral) nortriptyline 10–25 mg at night (titrated weekly up to a maximum daily dose of 75 mg at night).
- (Oral) duloxetine 30 mg daily (titrated weekly up to a maximum daily dose of 60 mg twice a day).

NMDA receptor antagonists

Ketamine is used in difficult-to-control pain management and opioid-induced hyperalgesia in highly specialised palliative care and pain medicine practice.

Anti-inflammatory pain medications

NSAIDs

Non-steroidal anti-inflammatory drugs (NSAIDs) possess certain advantages such as widespread availability and low cost, particularly when clinicians can carefully select suitable patients to avoid potentially serious adverse effects. While NSAID-related COX1 inhibition causes gastrointestinal and renal toxicities, COX2 inhibition causes cardiovascular toxicities.

Recommended doses

- (Oral) ibuprofen 200–400 mg 8-hourly.
- (Oral) celecoxib 100 mg 12-hourly.

Corticosteroids

Corticosteroids are commonly used to relieve inflammatory pain of bone, visceral (e.g., liver capsular), neurological (intracranial cerebral metastasis and raised intracranial pressure, spinal cord compression), origin soft tissue infiltration (head and neck tumurs, abdominal and pelvic tumours) and tenesmus (pain due to rectal tumour invasion) while obtaining beneficial effects, including appetite stimulation and increased wakefulness. Clinicians should be vigilant to monitor for potential acute adverse effects, including hyperglycaemia, immunosuppression, insomnia and psychiatric complications. Similarly, long-term adverse effects include proximal myopathy, Cushinoid habitus and osteoporotic complications.

Recommended doses

- (Oral/subcutaneous) dexamethasone 4–8 mg daily in the morning (16 mg in spinal cord compression).

Antispasmodic pain medications

Skeletal muscle spasm

Skeletal muscle spasms are a common symptom in neurological diseases, including neurodegenerative conditions. Skeletal muscle-specific relaxants provide targeted therapy in this setting.

Recommended doses

- (Oral) clonazepam 0.5 mg daily (up to a maximum daily dose of 2 mg twice a day).
- (Oral) baclofen 5 mg three times a day (up to a maximum daily dose of 25 mg three times daily).
- Local therapy with botulinum toxin is proven to be effective in pain related to contractures in neurological diseases.

Smooth muscle spasm

Visceral organ-related muscle spasms are commonly experienced by patients with intra-abdominal malignant or non-malignant pathologies.

Recommended doses

- (subcutaneous) hyoscine butylbromide 20 mg 4-hourly (up to a maximum daily dose of 120 mg per day). Oral route only effective in gastrointestinal pathologies due to limited bioavailability.

- (subcutaneous) hyoscine hydrobromide 0.4 mg 4-hourly (up to a maximum daily dose of 1,600 mg per day).

Other treatment modalities

Radiotherapy

Radiotherapy is an effective and durable modality of pain relief in malignancy-related pain syndromes. However, availability and cost restrict access to radiation in most healthcare systems. Palliative intent radiation for pain control can be delivered in a short course (less than 10 fractions) for most patients.

Patients should be warned about the immediate post-radiotherapy flare-up of pain, and necessary measures should be taken to cover this temporary side effect. Indeed, pain response to radiotherapy can take up to 2–3 weeks.

Chemotherapy and immunotherapy

Palliative intent chemotherapy and immunotherapy have proven benefits towards improving pain related to malignancies. To clarify the above management decisions, consultation with a clinical oncologist and/or a clinical haematologist is suggested.

Anti-resorptive therapy

Bisphosphonates are proven to be an effective measure in pain management (as part of skeletal-related event reduction) in multiple malignancies including breast, prostate and multiple myeloma.

Parenteral preparations are preferred to reduce malignancy-related skeletal events. Osteonecrosis of the jaw is a serious complication experienced by a limited number of patients who receive bisphosphonates.

Recommended doses (in patients with normal renal functions)

- (Intravenous) zoledronic acid 4 mg (usually monthly).
- (Intravenous) pamidronate 90 mg (usually monthly).

Invasive procedures

Application of invasive procedures for pain control in palliative care should be consistent with a patient's overall care goals. Notably, nerve blocks carry impressive safety and effectiveness data when carried out by experienced proceduralists (pain specialists) for radiological or anatomical guidance. Generally, patients' tendency to bleed is a common contraindication for most nerve block procedures. Table 4 presents the most common types of nerve blockage.

Table 4. Common types of nerve blocks for pain management

Type of block	Use
Coeliac plexus	Pancreatic cancer
Stellate ganglion	Upper extremity pain
Ganglion impar	Perineal pain
Brachial plexus	Upper limb pain
Lumber sympathetic	Lower limb pain
Peroneal/popliteal	Lower limb ischaemia pain

Epidural and intrathecal medication delivery systems provide effective pain management for selected group of patients with intractable pain when other non-invasive means are exhausted. However, necessary expertise and lack of resources limit its use in most healthcare systems.

Physical therapies

Correct device and equipment selection by a qualified physiotherapist and/or occupational therapist is useful in minimising pain related to malignant and non-malignant pain. This

is particularly the case in non-malignant neurological pathologies, including progressive neurodegenerative diseases.

Psychotherapy

The concept of total pain describes psychological contributions towards physical pain. Well-guided relaxation and meditation training can alleviate physical pain—hence, the requirement for effective pain relief medication.

Please refer the pain management guidelines for adults with cancer published by national cancer control programme with the ministry of health, nutrition and indigenous medicine in November 2017 (ISBN978-955-0505-99-9).

References

1. Cherny NI, Fallon M, Kaasa S, Portenoy RK, Currow D. Oxford textbook of palliative medicine: Oxford University Press, USA; 2015.
2. Wong DL, Baker CM. Smiling face as anchor for pain intensity scales. Pain. 2001;89(2):295-7.
3. Abbey J, Piller N, Bellis AD, Esterman A, Parker D, Giles L, et al. The Abbey pain scale: a 1-minute numerical indicator for people with end-stage dementia. International journal of palliative nursing. 2004;10(1):6-13.
4. Organization WH, Organization WH. WHO's cancer pain ladder for adults. 2014.
5. Twycross R, Wilcock A. Palliative care formulary (PCF4). BMJ Case Reports. 2011:2011.

CHAPTER 6

Gastrointestinal Symptoms

Introduction

Common gastrointestinal problems encountered in palliative care include, anorexia, nausea, vomiting, hiccups, diarrhoea and constipation.

Objective

The objective of this chapter is to gain knowledge regarding assessment and management of common gastrointestinal problems in patients receiving palliative care.

Anorexia

Introduction

Anorexia and cachexia are part of a complex metabolic process found in many end-stage illnesses. This impacts significantly on quality of life and can cause anxiety and distress for patients, perhaps even more so for carers.

Assessment

The assessment should be comprehensive, extending beyond calculating the patient's caloric intake versus their body weight. It is worth considering whether monitoring a patient's weight is really necessary, as this may result in increasing anxiety regarding weight loss. A nutritional assessment needs to be holistic. It should include the emotional, social, cognitive and biochemical aspects of nutrition

and diet. Each assessment should also be individualised, taking the patient's condition and stage of illness into consideration.

- **Look for any reversible problems** that may exacerbate anorexia, including: pain, breathlessness, depression, ascites, nausea & vomiting, constipation, dysphagia, heartburn, gastritis, anxiety and medication.
- Oral problems: such as dry mouth, ill-fitting dentures, ulcers, and candidiasis.
- Odors: cooking smells, incontinence, fungating lesions and fistulae can contribute to anorexia.
- Delayed gastric emptying (for example due to local disease, autonomic neuropathy) causing early satiety and vomiting of undigested foods.
- Fatigue is commonly associated with anorexia & cachexia.
- Ask patient and carer about their perspectives on weight, body image, nutrition and dietary intake.

Box 1: Assessment of anorexia

- **Assessment should be:**
  - **Holistic**: emotional, social, cognitive and biochemical aspects of nutrition
  - **Individualised**: consider the patient's condition and stage of illness
- **Look for any reversible problems**

Management

The basis for managing anorexia is acceptance of the fact that, in advanced illness, anorexia is due to the disease. Unlike anorexia nervosa, anorexia in palliative care patients is not an emotional disorder. Advanced disease often results in a set of inter-related symptoms called cachexia. This includes anorexia, loss of body mass and general debility. These are not the results of starvation. Rather, inability to eat well is part of the syndrome. Cachexia is due to metabolic changes, which in turn is due to the advanced disease itself. The main principle of management is to focus on food and drink as ways of promoting quality of life, rather than as ways of curing illness.

Non-pharmacological management

- Address patient and carer concerns about the importance of providing nourishment.
- Explain that a gradual reduction in oral intake is a natural part of the illness.
- Previous dietary advice given regarding diabetes and high cholesterol may be relaxed.
- Make sure mouth discomfort, nausea, constipation, difficulties in chewing, and swallowing are addressed and corrected. Continue treatment for any or all of these as long as it is needed. **It is particularly important to have regular bowel habits**.
- Encourage eating with family and friends, away from the bedroom.

- Manage the environment: introduce fresh air, pleasant surroundings and compatible companions. Eliminate unpleasant food smells. Use unperfumed cleaning materials, disinfectants and air fresheners when possible. Avoid fragrant flowers with a strong smell.
- If patient takes alcohol usually, a glass of wine or alcohol before meals can bring enjoyment and stimulate appetite. But make sure alcohol does not interact with medications.
- Rinse the mouth or cleanse the teeth and dentures often with water. Freshen the face and hands with a washcloth before meals. In hot weather, keep a moistened washcloth in the fridge.
- Chewing gum or sucking sugar-free sweets may promote saliva flow which helps to maintain oral health. Pineapple is also helpful, but too much of it may cause tooth erosion.
- Eat a small meal, two to three hours apart, rather than trying to have three solid meals a day. It is better to eat something small and enjoyable than to struggle to eat something that is "good for the patient". Allow for whims and fancies for favourite foods.
- Alterations in taste, a tendency to nausea, or mouth discomfort may change food preferences. If things taste too sweet, try adding sour (lemon or vinegar) or salt. If food tastes too strong, try mixing it with bland foods such as milk, rice, or potato. If food is too bland, try adding sugar, salt, lemon and/or herbs.
- Allow to experiment with warm, cold and frozen foods.
- Allow patient to eat what they like, when they like – "It is never too early in the day for pudding or too late for breakfast"

Medications: Pharmacological management

The following drugs are of limited or temporary benefit but worth considering, as they may improve quality of life of a patient. The potential side effects and risks of medication should be taken into account when prescribing.

- Corticosteroids: these have an established role in the short-term improvement of appetite. Effect is rapid but tends to decrease after 3–4 weeks. May also help to reduce nausea, improve energy and general feeling of wellbeing. However, there is often no significant effect on nutritional status.
    - Starting dose: oral dexamethasone 4 mg or prednisolone 30 mg (given in the morning). Consider need for gastric protection, such as H_2-receptor blocker or proton pump inhibitor. Prescribe for 1 week and if helpful, reduce gradually to lowest effective dose. If there is no effect, stop. Assess and review dose regularly.
- Progestogens: May stimulate appetite and weight gain in patients with cancer. May take a few weeks to take effect but benefit is more prolonged than steroids. More appropriate for patients with a longer prognosis.
    - Megestrol acetate: starting dose 160 mg/daily and then after 2 to 3 weeks assess and review. For appetite stimulation, lower doses are as effective as higher doses. There is no evidence for an optimal dose. The maximum dose is 800 mg daily. Reduce dose gradually if it has been used for more than 3 weeks (adrenal suppression).
- Prokinetics: Used for early satiety, delayed gastric emptying, gastroparesis or nausea.

- Metoclopramide 10 mg or domperidone 10 mg given three times a day, 30 minutes before meals.

Box 2: Management of anorexia

- Basis for managing anorexia is acceptance of the fact that, it is due to the advanced disease itself
- Main principle of management is to focus on food and drink as ways of promoting quality of life
- Non-pharmacological aspects play an important role
- Medicines are of limited or temporary benefit but worth considering as a measure of improving quality of life

Nausea and Vomiting

Introduction

Nausea and vomiting affect the majority of patients with advanced cancer and other life-limiting illnesses. The management of nausea and vomiting in these patients can be complex. Many of the published guidelines and recommendations are based on a theoretical understanding of the mechanisms of nausea and vomiting and there is little robust clinical evidence to support practice.

As well as managing the actual nausea and vomiting, it is essential that the consequences are considered. Individuals with protracted nausea and vomiting are likely to have poor control of other symptoms (particularly if they are unable to manage their usual medication) and usually have reduced oral intake of food and fluid – contributing to weight loss and fatigue. The potential for significant dehydration and hypokalaemia must be borne in mind along with the potential for increased adverse drug reactions from relatively commonly prescribed medications such as non-steroidal anti-inflammatory drugs (NSAIDs), angiotensin-converting enzyme inhibitors, and diuretics which may require to be temporarily discontinued until vomiting is controlled.

The effect on family and cares of looking after someone with nausea and/or vomiting can be profound. The patient and their family will therefore usually require emotional and spiritual care as well as physical support.

Regurgitation

Obstruction of the oesophagus and consequent regurgitation can be reported as vomiting. It is important to differentiate regurgitation from vomiting, in order to avoid delay in seeking endoscopic intervention if it is appropriate. Regurgitation will never be relieved by anti-emetics, but associated persistent nausea may respond to the appropriate medication.

Assessment

Box 3: Assessment of a patient with nausea and vomiting

- Triggers, exacerbating and relieving factors
- Bowel habits, symptoms of bowel obstruction
- Look for offending medications
- Examination:
    - Signs of dehydration, sepsis and drug toxicity
    - Central nervous system causes for vomiting, like increased ICP.
    - Abdomen (e.g., organomegaly, bowel sounds, succussion splash).
- Blood investigations:
    - Urea and electrolytes, liver function tests, calcium, blood glucose, UFR & CRP.

Management

- Correct the correctable (e.g., renal function, hypercalcaemia, constipation)
- Consider non-pharmacological measures first
- Choose an anti-emetic appropriate to a likely identified cause. A combination of anti-emetics may be appropriate
- Adjuvant steroid and/or benzodiazepine may be combined with the prescribed anti-emetic drug(s)
- Try to avoid the concurrent prescribing of prokinetics (e.g., metoclopramide – caution in the use of prolonged higher doses, monitor for extrapyramidal side effects) and anticholinergic medication (E.g.: Cyclizine). Refer for specialist advice.
- Consider the route of administration of medication. The oral route may not provide adequate absorption or may be inappropriate as a result of nausea or vomiting. Buccal or sublingual medication administration may be helpful, but may trigger symptoms of nausea or vomiting in susceptible individuals. The parenteral route may reduce tablet burden, which may be a contributing factor to nausea.

Non-pharmacological management

- Attention to detail with oral care and hygiene (commonly altered taste and thrush) are important.
- Regularise bowel habits. Constipation is a relatively common cause of nausea.
- Encourage eating regular small palatable portions rather than having large meals.
- Avoid strong smells while preparing food.
- Cold rather than hot meals may be helpful.

- Provide a calm and reassuring environment.

Pharmacological management

Almost all causes of nausea and vomiting can be placed in the following categories, and each are associated with management with a specific drug or class of drugs.

Cause	Clinical picture	Medication
Clinical toxicity • Carcinomatosis • Chronic inflammation • Metabolic/ biochemical upsets/drugs	persistent often severe vomiting, little relief from vomiting or retching	1. Haloperidol: 500 micrograms to 1.5 mg orally or 500 micrograms to 1 mg subcutaneously daily (start with lower doses in renal failure and elderly and frail patients) 2. Levomepromazine: 2.5-5 mg subcutaneous injection 12-hourly or 5-15 mg in 24 hours by continuous subcutaneous infusion. Change to oral route if symptoms resolve. 3. Prochlorperazine: 5-10 mg orally 3-4 times a day 4. Ondansetron: (cytotoxic/chemotherapy induced) 4 mg orally (or subcutaneously) twice daily
Gastric stasis/outlet obstruction • Opioids, anticholinergics	- intermittent nausea often relieved by vomiting (often little nausea until	1. Metoclopramide: 10-20 mg orally four times a day or 30-80 mg/24 hours by subcutaneous infusion 2. Domperidone 10 mg 3 times a day orally. 3. Erythromycin 250 mg 3-4 times daily

• Local tumour • Autonomic failure • Hepatomegaly • Peptic ulceration • Hypercalcemia	immediately prior to vomiting) - early satiation - reflux, hiccup	4. If colic or no response: seek advice 5. Consider dexamethasone (if liver metastases or extrinsic compression) 4-8 mg daily reducing after 3 days, aiming to stop or lowest maintenance dose 6. Consider endoscopic stenting
Oesophageal or mediastinal disease • Tumour • Toxins • Inflammation • Infection (e.g., candida, herpes simplex) • Foreign body (e.g., stent)	- regurgitation - dysphagia. - little nausea or relieved after food regurgitated -	1. Rantidine 150 mg twice daily, omeprazole 20-40 mg BD/Daily 2. Endoscopic stenting 3. Radio/chemotherapy 4. Consider dexamethasone 4- 8mg daily reducing after 3 days, aiming to stop or lowest maintenance dose. 5. Antifungals/antivirals/antibiotics (Antiemetics often ineffective)
Bowel obstruction • Abdominal carcinomas •Autonomic neuropathy	- may be partial/intermittent initially. - nausea often improved after vomiting. - increased nausea, +/- colic, +/- faeculent vomiting in advanced/co	Medical management if surgery inappropriate. Seek specialist advice early. 2 main types:- a) Peristaltic failure - metoclopramide 10 mg TDS or domperidone 10 mg TDS b) Mechanical obstruction 1. If colics: hyoscine-N-butylbromide 10-20 mg oral or 20-40 mg inj may be administered by slow IV, IM or SC several times a day. A maximum daily dose of 100 mg should not be exceeded Or

• Hypokalaemia (Exclude constipation)	mplete obstruction	hyoscine butylbromide 150-300 micrograms orally, 200-400 micrograms subcutaneously or 1 mg/72 hours via transdermal patch. 2. Levomepromazine 3. Cyclizine 25-50 mg orally or subcutaneously three times per day +/- haloperidol 4. NG tube if persistent vomiting
	- Headache +/- cranial nerve signs - Impaired consciousness	1. Cyclizine 25-50 mg orally or subcutaneously three times per day + dexamethasone 8-16 mg/day (if raised intracranial pressure)
Cranial disease/treatment • Intracranial pressure • Radiotherapy • Brainstem/meningeal disease **Movement related** • Vestibular disease	- Vertigo - dizziness with nausea - Movement-related vomiting	1. Cyclizine 25-50 mg orally or subcutaneously 3 times/day 2. Cinnarizine: 30 mg orally initially then 15 mg 3 times/day 3. Levomepromazine 2.5-5 mg subcutaneous injection 12-hourly or 5-15 mg in 24 hours by continuous subcutaneous infusion. Change to oral route if symptoms resolve. 4. Prochlorperazine,5-10 mg orally 3-4 times a day

- Base of skull tumour
- Motion sickness

Cause unclear/multiple causes	1. Metoclopramide: increasing to 30-80 mg/24 hours by subcutaneous infusion 2. Levomepromazine: 3-6 mg twice daily orally or 2.5-5 mg twice daily by subcutaneous injection or occasionally, 5-15 mg in 24 hours by continuous subcutaneous infusion but likely to cause sedation 3. Trial of dexamethasone: 8 mg daily, reducing after 3 days aiming to stop or to lowest maintenance dose 4. Consider higher centre origin pain, fear, anxiety - benzodiazepines e.g., lorazepam 500 micrograms to 1 mg, diazepam 2-5mg

For All persistent problems, seek specialist advice

- For persistent vomiting, attention to hydration and nutritional status is essential.
- Despite logical and appropriate treatment, the patient may continue to vomit especially if there is a duodenal/gastric outflow obstruction or high small bowel obstruction.
- If surgical intervention for an obstructing lesion is neither appropriate nor possible, then interventional endoscopic stenting may be an option. The passage of a nasogastric tube followed by the placement of a venting gastrostomy can be preferable to the persistent vomiting associated with upper bowel obstruction.
- Continue to take pain medication as severe pain can make nausea worse.

Box 4: Management of a patient with nausea and vomiting

- There are various aspects of non-pharmacological management
- Identifying the underlying cause/mechanism of nausea and vomiting is important for pharmacological management as the specific drug or class of drugs to be used depends on that; choose the appropriate route
- When vomiting is persistent, attention to hydration and nutritional status is essential
- If surgical intervention for an obstructing lesion is neither appropriate nor possible, then interventional endoscopic stenting may be an option

Hiccups

Introduction

Persistent hiccups are a frustrating experience for palliative care patients, and can have a profound impact on their quality of life. Currently treatment of intractable and persistent hiccup is based on patients' and clinicians' preferences and not on any significant evidence from randomized controlled trials. Pharmacological treatment should take into account the potential side effects and risks of medication.

Assessment

Careful assessment is required to identify the cause. Consider severity, duration and impact on a patient's quality of life.

Box 5: Causes for hiccups

- Gastric stasis and distension (the most common cause)
- Gastro-oesophageal reflux
- Metabolic derangements: hypokalaemia , hypocalcaemia , hypocarbia, uraemia, DM, magnesium deficiency
- Pharmacologic agents: corticosteroids, benzodiazepines, chemotherapy, opioids
- Diaphragmatic/phrenic nerve irritation: tumour, infection, inflammation
- Hepatic disease/hepatomegaly
- Cerebral causes (e.g., tumour, metastases)

Management

- Treat reversible causes.
- Hiccups often stop spontaneously. Treatment is only required if hiccups are persistent.
- Try simple physical manoeuvres initially and those that have worked previously.

Non-pharmacological management

Simple measures or 'home remedies' can be effective. These include:

- Sipping ice water or swallowing crushed ice
- Breathing into a paper bag, particularly if the patient is hyperventilating
- Interrupting normal breathing, e.g., holding breath
- Drinking from wrong/opposite side of a cup
- Rubbing the soft palate with a swab to stimulate the nasopharynx.

Pharmacological Management

- Peppermint water 10 ml twice daily
- Antacid medication containing simeticone, 10 ml between meals and at bedtime when required
- Prokinetic: domperidone or metoclopramide oral 10 mg, 8-hourly.
- Treat any gastro-oesophageal reflux with a proton pump inhibitor.
- Dexamethasone oral 4-8 mg in the morning may reduce compression/irritation if the patient has a hepatic, mediastinal or cerebral disease/tumour. Stop if no benefit after a week.

(Peppermint water and prokinetics, e.g. metoclopramide, should not be used concurrently because of their opposing actions on the gastro-oesophageal sphincter)

Other options:

- Oral haloperidol 500 micrograms to 1 mg if required 8-hourly, follow up with a maintenance dose of 1 to 3 mg at bedtime
- Oral baclofen 5-10 mg BD or TDS (avoid abrupt withdrawal)
- Oral levomepromazine 3-6 mg at bedtime
- Chlorpromazine 25-50 mg daily (avoid if hypotensive)
- Nifedipine 5-20 mg, if required 8-hourly (avoid if hypotensive).
- Anti-convulsants such as gabapentin or phenytoin

Patients and carers should be advised that initial treatment for persistent hiccups should be reviewed after 3 days and changed if there is little or no improvement. This may mean an increase in the dose or a change of medication.
If hiccups are difficult to control, advice should be sought from specialist palliative care colleagues.

Diarrhoea

Introduction

Diarrhoea is the passage of frequent loose stools and can be defined as the passage of more than 3 unformed stools within a 24-hour period. Patients may describe diarrhoea as a single loose stool, frequent stools of normal or even hard consistency, or fecal incontinence, so careful clarification of the term is always required. Diarrhoea can be a distressing and exhausting symptom for both the patient and their cares. It is important to remember that it can be an embarrassing symptom and impact on dignity, mood and relationships.

Assessment

Take a careful history detailing:

- Frequency of defecation
- Nature of stools including consistency, colour
- Presence of mucus or blood
- Timing of the problem
- Current and recent medications such as laxatives, broad spectrum antibiotics
- Recent foreign travel.

Examination and investigations:

Exclude fecal impaction and intestinal obstruction: rectal examination, abdominal palpation. Abdominal x-ray may be required to confirm the diagnosis.

Box 6: Possible causes for diarrhoea

- ALWAYS check for *Clostridium difficile* infection`
- Drugs including laxatives, antacids, antibiotics, non-steroidal anti-inflammatory drugs (NSAIDs), chemotherapy agents, disaccharide-containing (sugar-free) elixirs, iron.
- Radiotherapy, particularly when involving the abdomen or pelvis.
- Obstruction: fecal impaction, narcotic bowel syndrome (severe constipation caused by opioid analgesia) resulting in spurious diarrhoea as overflow
- Malabsorption
- Pancreatic carcinoma, pancreatic islet cell tumours, carcinoid tumours.
- Concurrent disease, for example diabetes mellitus, hyperthyroidism, pancreatic insufficiency, inflammatory bowel disease such as Crohn's disease, ulcerative colitis, gastrointestinal infection.
- Diet, for example high fibre, fruit, hot spices, alcohol

Management

- Send stools for *Clostridium difficile* toxins if antibiotics have been used recently, patient is on PPIs or having fever

General measures

- Drink extra fluids frequently. Use ORS if large volume diarrhoea or persistent diarrhoea.
- Advise to continue eating

- Carrot soup helps to replace vitamins and minerals. Carrot soup contains pectin. It soothes the bowels and stimulates the appetite.
- Foods that may help reduce diarrhoea are rice and potatoes.
- Give bananas and king coconut (for their potassium)
- Give 5-6 small meals rather than 3 large ones.
- Add nutmeg to food

- Avoid:
  - Coffee, strong tea and alcohol
  - Raw foods, cold foods, high-fibre foods, food containing much fat
  - Test benefit of avoiding milk and cheese (yogurt is better tolerated). It may be difficult to digest lactose-rich foods such as milk. Avoid drinking milk in cases of infective diarrhoea. Even if not normally lactose intolerant, diarrhoea caused by a virus can cause sensitivity to milk products for a time after the diarrhoea has cleared.
- Gradually reintroduce proteins and then fats to the diet as diarrhoea resolves.

Pharmacological management

1. Give constipating drugs (if it is not an infective diarrhoea or spurious diarrhoea)
   - Loperamide 4 mg once, then 2 mg per loose stool to maximum 16 mg/day
   - Oral morphine 2.5–5 mg every 4 hours (if severe).
   - Codeine 10 mg 3 times daily (up to 60 mg every 4 hours)

(Use a combination if not responding and seek specialist help if still no response)

2. Suggested pharmacological management for patients taking opioid analgesia
    - Exclude opioid-induced overflow diarrhoea.
    - Consider converting morphine from slow-release tablets to normal-release preparation to improve absorption, or use continuous subcutaneous infusion.
    - Use medications for treatment of constipation as above

3. Further considerations
    - Persistent diarrhoea can cause depletion in vitamins, minerals and trace elements that are important for normal body functions and may require replacing, for example sodium, potassium, magnesium and zinc.
    - Glucose is pro-absorptive in the bowel. Giving a glucose or electrolyte drink may help diarrhoea, as well as replacing important losses.
    - Bacterial overgrowth or imbalance of the normal gut flora may cause diarrhoea despite negative stool cultures for pathogens, especially after ileo-colic resection or surgical formation of blind loops of gut. It may be worth considering discussing a course of metronidazole with GI specialists.
    - Methylcellulose tablets can be tried.
    - Octreotide may reduce high-output diarrhoea following ileostomy or colectomy, and has been used in carcinoid syndrome, graft versus host disease and other cancer

and AIDS-related diarrhoeas. It can be given by subcutaneous infusions, suggest seeking specialist advice.

- Candida infection has been described causing secretory-type diarrhoea and can be treated with oral nystatin.
- Referral to a GI surgeon (for example for anal plugs, incontinence pads).
- Patients with HIV or AIDS: Patients with HIV or AIDS frequently have problems with diarrhoea, it is usually infective, but the diagnosis, isolation of pathogens, and treatment can be very complex. Specialist advice should be sought.

Special considerations

- Careful explanation required on constipation with overflow as it may be difficult to understand why diarrhoea is being treated with laxatives.
- Offer skin care advice for anal area such as:
    - wipe with moist toilet paper or cotton wool
    - avoid using baby wipes because they often contain alcohol
- Wash area after an episode of diarrhoea, use a shower attachment or a soft, disposable cloth and non-scented soap before patting the area dry.
- Apply a thin layer of durable barrier film or cream.
- Wear cotton underwear and avoid tight-fitting clothing.

Box 7: Management of diarrhoea

- It is important to differentiate true diarrhoea from spurious diarrhoea secondary to obstruction/severe constipation
- Exclude *Clostridium difficile* infection if antibiotics have been used recently, patient is on PPIs or having fever
- Ensure adequate hydration. Advise to continue eating while avoiding food rich in proteins and fats
- Constipating drugs (e.g., loperamide) are indicated for non-infective and non-spurious diarrhoea
- Offer skin care advice for anal area

Constipation

Introduction

Constipation is one of the most common problems experienced by patients in palliative care, particularly those with advanced cancer. It can cause extreme suffering and discomfort to the patient. Therefore, it needs to be identified early and managed appropriately. Constipation can be the passage of small, hard feces infrequently or with difficulty, and less often than is normal for that individual. Constipation can be complex and therefore may require specialist advice if first line treatment regimens are not successful.

Assessment

A full assessment of the patient should be directed at identifying the problem, its complications and likely causes.

- Current pattern of bowel motions (frequency, consistency, ease of passage, blood present, pain on passing stool, overflow diarrhoea)
- Abdominal pain: colicky, diffuse discomfort
- Clinical features of bowel obstruction:
    - absolute constipation, abdominal pain, nausea vomiting, abdominal bloating
- Complications:
    - urinary retention
- Secondary effects of illness (reduced consciousness, dehydration, immobility, poor diet, anorexia)
- Current and previous laxatives taken regularly (or as needed) and their effectiveness
- Causes of the constipation

Box 8: Causes of constipation

Organic causes

- Pharmacological agents: antacids, anti-epileptics, anti-emetics (5-HT3 antagonists), antihypertensives, antiparkinsonians, anticholinergics, antidepressants, antitussives, antidiarrhoeals (when used in excess), cancer chemotherapies (vinca alkaloids), diuretics (when causing dehydration), iron (orally administered), opioid analgesics, neuroleptics
- Metabolic disturbances: dehydration (fever, vomiting, polyuria, poor fluid intake, diuretics), hypercalcaemia, hypokalaemia, uraemia, hypothyroidism, diabetes
- Neurological disorders: cerebral tumours, spinal cord involvement, sacral nerve infiltration, autonomic failure (primary such as Parkinson's disease, multiple sclerosis, motor neurone disease; or secondary to cancer or diabetes)
- Structural abnormalities: pelvic tumour mass, radiation fibrosis, painful anorectal conditions (haemorrhoids, anal fissure, perianal abscess), uncontrolled cancer-related pain or other pain such as movement-related pain or breakthrough pain.

Functional factors

- Diet: Poor appetite and low amounts of food intake, low-fibre diet, poor fluid intake
- Environmental: Lack of privacy, comfort or assistance with toileting
- Other factors: Advanced age, inactivity, decreased mobility, confined to bed, depression, sedation
- Examination and investigations

- Examination and investigations
  - Abdominal and rectal or stomal examination (unless it would cause undue distress for the patient): look for rectal loading, tumours, blood etc.
  - To exclude bowel obstruction and assess extent of fecal loading, an X-ray may be useful.

Management

The aim of management is to achieve comfortable defecation, rather than any particular frequency of bowel motion.

General measures

- Ensuring privacy and comfort to allow a patient to defecate normally; a foot stool to elevate knees may help.
- Increasing fluid (2 liters per day if able) and fiber intake within the patient's limits.
- Encouraging activity and increased mobility within the patient's limits
- Anticipating the constipating effects of pharmacological agents, such as opioids, and providing laxatives prophylactically.
- Use oral laxatives if possible in preference to alternative routes of administration.
- Treatment per rectum may be necessary (alone or in combination with oral laxatives) in patients who cannot tolerate or swallow oral laxatives, when there is fecal impaction or in patients with spinal cord lesions and disrupted innervation to the lower bowel. When constipation is diagnosed, a spontaneous bowel action may

not be possible if fecal impaction is present. In these circumstances, an enema or suppository may be needed.

- Do not give drugs per rectum if rectum is ballooned and empty.
- **Generally, a combination of a softener and a stimulant is recommended for the management of constipation in palliative care**
- If oral laxative treatment is given alone, a bowel action should be expected within 3 days. If this does not occur, the use of a combination of softening and stimulant laxatives is essential. The dose should then be titrated upward on a daily or alternate day basis until a bowel action is achieved.
- The occurrence of colic means that the dose of softening laxative should be increased relative to that of the stimulant, whereas the development of fecal leakage suggests a need to reduce the softening dose and perhaps increase that of the stimulant.
- Bulking agents, such as isphagula, methyl cellulose and bran, if taken with inadequate water can precipitate intestinal obstruction through formation of a viscous mass in the bowel. Therefore, should not be routinely used in palliative care.
- Patient preferences should be taken into consideration.

Specific treatment

First line treatment (stimulant ± softener)

- Combination of a softener (e.g., polyethylene glycol and electrolytes or lactulose) and a stimulant (e.g., senna or sodium picosulphate) according to patient needs.

Second line treatment (rectal)

- Rectal suppository and enema (bisacodyl suppository, phosphate enema, sodium citrate, glycerol suppository as lubricant or stimulant.)
- Consider use of a peripherally-specific opioid antagonist, e.g., methylnaltrexone, if patient taking an opioid

Third-line treatment

- Manual evacuation

For paraplegic or bedbound patient

- Adjust laxatives or loperamide to keep stool firm, but not hard.
- Use rectal intervention every 1 to 3 days to avoid possible impaction resulting in fecal incontinence, anal fissures or both.

Constipation in the dying patient

Although constipation can still be a problem in the last days of life, a patient's deteriorating functional status can mean that the symptoms of constipation become less apparent as they become comatose and, as such, the management of constipation becomes a lower priority in their overall care. In the last few days of life, when patients are no longer able to receive medication and their level of consciousness diminishes, oral laxatives should be discontinued. The need for rectal care is likely to be rare at this stage.

Box 9: General advice on discharge regarding gastrointestinal symptoms

Anorexia, nausea, vomiting

- Explain that a gradual reduction in oral intake is a natural part of the illness
- Previous dietary advice given regarding diabetes and high cholesterol may be relaxed.
- Encourage eating with family and friends, away from the bedroom.
- Manage the environment:
  - Introduce fresh air and pleasant surroundings
  - Compatible companions.
  - Eliminate unpleasant food smells.
  - Use unperfumed cleaning materials, disinfectants and air fresheners when possible.
  - Avoid fragrant flowers with a strong smell.
- Rinse the mouth or clean the teeth and dentures often with water.
- Freshen the face and hands with a washcloth before meals.
- Chewing gum or sucking sugar-free sweets or fruits like pineapple/lime/ oranges may promote saliva flow which helps to maintain oral health.
- Take small meals, two to three hours apart, rather than trying to have three solid meals a day. Allow for whims and fancies for favorite foods.
- Alterations in taste, causes nausea. If things taste too sweet, try adding sour (lemon or vinegar) or salt. If food tastes too strong, try mixing it with bland foods such as milk, rice, or potato. If food is too bland, try adding sugar, salt, lemon and/or herbs.
- Allow to experiment with warm, cold and frozen foods.
- Allow patient to eat what they like, when they like.

Hiccups

- Try simple physical manoeuvres initially and those that have worked previously; if still persistent medications will be prescribed

Diarrhoea

- Drink extra fluids frequently. Use ORS if large volume diarrhoea or persistent diarrhoea occurs
- Advise to continue eating; avoid coffee, strong tea, alcohol, raw foods, cold foods, high-fibre foods, food containing much fat; carrot soup, bananas and king coconut are beneficial
- Gradually reintroduce proteins and then fats to the diet as diarrhoea resolves
- Skin care advice for anal area

Constipation

- Ensure privacy and comfort
- Increase fluid and fibre intake
- Increased mobility within the patient's limits

Seek medical advice for pharmacological management of these symptoms

References

1. Dolan EA. Malignant bowel obstruction: a review of current treatment strategies. Am J Hosp Palliat Care. 2011;28(8):576-82.
2. Hisanaga T, Shinjo T, Imai K, Katayama K, Kaneishi K, Honma H, Takagaki N, Osaka I, Matsuo N, Kohara H, Yamaguchi T, Nakajima N. Clinical Guidelines for Management of Gastrointestinal Symptoms in Cancer Patients: The Japanese Society of Palliative Medicine Recommendations. J Palliat Med. 2019 Aug;22(8):986-997. doi: 10.1089/jpm.2018.0595. Epub 2019 Apr 2. PMID: 30939064.
3. Feuer DJ, Broadley KE. Corticosteroids for the resolution of malignant bowel obstruction in advanced gynaecological and gastrointestinal cancer. 2000 [cited 2018 Oct 08]; Available from:https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD001219/epdf/standard
4. Feuer DDJ, Broadley KE, Shepherd JH, barton DP. Surgery for the resolution of symptoms in malignant bowel obstruction in advanced gynaecological and gastrointestinal cancer. 2000 [cited 2018 Oct 08]; Available from: https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD002764/full
5. Mercadante S, Casuccio A, Mangione S. Medical treatment for inoperable malignant bowel obstruction: a qualitative systematic review. J Pain Symptom Manage. 2007;33(2):217-23.
6. Ripamonti C, Mercadante S. Pathophysiology and management of malignant bowel obstruction. In: Hanks G, Cherny N, Kaasa S, Christakis NA, Portenoy RK, Fallon M, editors. Oxford Textbook of Palliative Medicine 4th ed. Oxford: Oxford University Press; 2010. p. 850-2.
7. Scottish Palliative Care Guidelines. 2014.
8. Tradounsky G. Palliation of gastrointestinal obstruction. Can Fam Physician. 2012;58(6):648-52, e317-21.

CHAPTER 7

Respiratory Symptoms

Breathlessness in Palliative Care

Introduction

Breathlessness is a subjective experience of breathing discomfort, which can only be described and interpreted by the patient. There is a complex set of interactions between physical, psychological and emotional factors which define breathlessness in an individual patient and these factors vary from patient to patient.

Assessment

- **Measurement of breathlessness**
  Breathlessness, being a subjective symptom, cannot be easily quantified, and there is no commonly agreed assessment tool. It is worthwhile to remember that measurable parameters such as pulmonary function testing or pulse oximetry readings are not representative of real-life feelings of the patient.
  When assessing breathlessness, it should reflect the patients' reporting of both severity and affective components. Any response to intervention must reflect patient-relevant outcomes such as reduction in intensity of breathlessness, a reduction in psychological distress, an increase in activity levels or a reduction in hospital admissions.

- **Investigating the breathless patient**
  Perform an investigation only if it provides information that will affect management and is consistent with in the goals of care of the palliative patient.
  This decision must be individualised for each patient.

Management

- **Goals of management**

  Breathlessness is a frightening feeling therefore it is important to provide a supportive environment and reassure the patient and the care givers that everything will be done to improve breathlessness.

  Ensure that treatment for the underlying disease is optimised in the context of disease trajectory, performance status and patients' wishes.

  Treat any reversible and treatable causes, which are contributing to the breathlessness

  For many patients, a potentially reversible cause will not be found and there will be multiple factors contributing and aggravating breathlessness. Therefore, the clinical approach would be to focus on improving the patients' experience of breathlessness and its impact on all aspects of their lives.

Symptomatic management of breathlessness includes both non-pharmacological and pharmacological management strategies brought together by a multidisciplinary team approach.

Management steps will be largely influenced by the illness trajectory. Patients who are acutely ill with short life expectancy will need pharmacological management of breathlessness introduced early on, while in all patients with chronic breathlessness should have non-pharmacological management strategies considered prior to starting pharmacotherapy for breathlessness.

- **Look for potentially reversible/treatable causes which may be contributing to the breathlessness**

Box 1: Potentially reversible/treatable causes which may be contributing to breathlessness

- Airway problems: e.g., bronchospasms, stridor
- Lung parenchymal problems: e.g., pulmonary infections, lymphangitis carcinomatosis
- Pleural pathology: e.g., pleural effusions,
- Circulatory problems: e.g., cardiac failure, pulmonary embolism, superior vena caval obstruction, anemia, pulmonary embolism, arrhythmia

- **Managing potentially reversible causes of breathlessness**

Cause	Management options
Bronchospasm	Bronchodilators Corticosteroids
Infection	Antibiotics (consider atypical pneunomias) Add corticosteroids if infective exacerbation of COPD
Pleural effusion	Therapeutic pleural aspiration, drainage, and pleurodesis
Pulmonary embolism	Anticoagulation (low molecular weight heparin is the preferred choice)
Heart failure	Diuretics Nitrates Anti-arrhythmics if indicated
Anaemia	Blood transfusion, iron
Lymphangitis carcinomatosa	Corticosteroids
Large airway obstruction	Radiotherapy Stenting if extrinsic compression Laser treatment for intraluminal cancer Brachytherapy Corticosteroids

- **Medications for treatable causes of breathlessness.**

Bronchodilators: Salbutamol 2.5-5 mg or ipratropium bromide 250-500 mcg by inhaler or spacer: Stop if no symptomatic benefit.
Sodium Chloride 0.9% 5 ml via nebulizer may help to make tenacious secretions less viscous

Steroids: trial of dexamethasone oral 4-8 mg daily or prednisolone 25-50 mg daily for lymphangitis or airways obstruction that has responded to steroids before. Benefit should be apparent within 4-7 days. Stop if no effect after a week.

Unless starting emergency therapy, give steroids in the morning.

Pharmacological management of breathlessness

- **Opioids:** Breathlessness, irrespective of cause, activates areas in the limbic system of the brain. This region is rich in opioid receptors and generates the conscious awareness of breathlessness and the associated sensation of unpleasantness. Morphine reduces the sensation of breathlessness and associated anxiety.

  When used in low doses and carefully-titrated morphine, does not cause significant respiratory depression.

  While on treatment, need to monitor patient response and side effects.

  Give as a therapeutic trial;

  - No opioid before: Immediate release morphine oral 2.5 mg, 4-6 hourly or as required or sustained release morphine oral 10-20 mg once a day for constant breathlessness.

    Increase slowly in steps by approxinately 30%, if tolerated. It is unusual to require doses more than 5-10 mg every 4-hourly.
  - If unable to take oral medication use the SC route morphine
  - Elderly, frail or those at-risk patients including

COPD or impaired renal function: morphine oral 1-2 mg, 6-8 hourly or as required

- Monitor closely for side effects specially constipation and drowsiness.
- If opioid is taken regularly for pain: 25%-50% increase in the morphine dose above its analgesic dose is recommended for control of dyspnoea. Titrate accordingly.

- **Anxiolytics**: Many patients with dyspnoea have related anxiety and a feeling of panic, particularly when intermittent acute attacks occur. Fear of a suffocating death is often present the following approaches can be usefully combined with morphine at the outset of treatment:

  Benzodiazepines: Longer-acting benzodiazepines are useful when there is severe anxiety or at night, when breathlessness and associated anxiety interrupt sleep.
  Diazepam 2-5 mg nocte or clonazepam oral or sublingually 0.5-1 mg nocte.
  Benzodiazepines with shorter half-lives can be useful in crisis situations but agitation/anxiety may manifest as the medication wears off.
  Lorazepam 0.5-2 mg sublingually during an attack of dyspnoea and panic can be very effective.
  Alternatives are alprazolam oral 0.25-1 mg or midazolam SC 2.5-5 mg.

- **Furosemide**: Nebulized furosemide has shown benefit in reducing breathlessness unrelated to its diuretic effect and appears to protect from bronchoconstriction.

- **Oxygen**: Hypoxic respiratory drive usually starts with PaO2 <8 kPa /60 mmHg (roughly equivalent to an oxygen saturation of 90%).

  Oxygen may be helpful in relieving breathlessness in patients who are hypoxic at rest or on exertion and should not be prescribed to relieve breathlessness in the non-hypoxic patient.

  Nonetheless, it is at times difficult to determine which patient will derive benefit from supplemental oxygen therapy based purely from their oxygen saturation.

  Therefore, at such times the best way to determine benefit would be by a trial of oxygen therapy

  Oxygen therapy may cause psychological and physical dependence in the patient and increase the anxiety levels, therefore prescribing oxygen should be a well thought out decision.

Counseling and reassurance of the patient that breathlessness can be relieved and that they will not be allowed to 'suffocate' in the terminal phase can give great relief to many patients who have experienced acute attacks of dyspnoea in the past

Non-pharmacological interventions for chronic breathlessness

A non-pharmacological approach is important in patients with end stage respiratory or cardiac disease.

Important measures such as appropriate positioning of the patient in bed, to letting a draught of air from a fan or from an open window is helpful in reducing breathlessness.

The following interventions have benefit in palliating breathlessness and should be considered in all patients with chronic breathlessness prior to starting pharmacological management.

Intervention	**Outcome**
pulmonary rehabilitation and exercise	• desensitise patient • reduces deconditioning • lowers ventilator demand and slows respiration
neuromuscular electrical stimulation (NMES)	• induces quadriceps contractions as an alternative to exercise
forward positioning	• fixes shoulder girdle • improves efficacy of accessory muscles
walking aid	• allows forward leaning and decrease work of breathing during exercises • increase patient confidence
breathing retraining/blow as you go "pursed lip breathing"	• promotes more efficient breathing pattern and improved gas transfer
facial cooling/hand held fan/piped medical air	• interrupts signals from upper airway to brainstem respiratory center
acupuncture	• stimulates of endogenous beta-endorphin release

anxiety-reducing interventions such as CBT	• addresses psychological and emotional components promotes self-mastery and delays spiral of inactivity and deconditioning
multi-professional breathlessness intervention clinic	• provides combination of non-pharmacological and pharmacological strategies • improves patient self-efficiency

Cough in palliative care

Introduction

Cough protects the lungs and the airways by clearing it of irritants and secretions. Therefore, coughing may be beneficial in certain groups especially those with productive cough.

Plan of management

- Treat any reversible underlying causes
- Consider disease-specific treatments, such as palliative radiotherapy or chemotherapy, where the mass effect of a tumour is the main cause of cough
- Symptomatic treatment: it is important to distinguish between a productive cough and a non-productive cough. Effective cough to clear the mucus should be the aim of therapy in a productive cough, unless the dying patient is too weak to expectorate. Dry cough should be suppressed once reversible causes are treated.

Symptomatic treatment of productive cough

Such options include:
Steam inhalation or nebulized sodium chloride 0.9% 2.5 ml QDS
Carbocysteine 500-750 mg per oral TDS
Physiotherapy with sputum clearance techniques
Nebulized salbutamol if there are bronchospasms
Antibiotics can be considered as a palliative measure when given to control infection which may be more effective in treating cough than symptomatic measures, i.e., offensive sputum which is suggestive of anaerobic infection may respond to metronidazole. Purulent secretions colonised with Gram-negative organisms can be treated with nebulized gentamicin 80 mg TDS with significant reduction in volume of secretions.
Radiotherapy has been found to be helpful in reducing bronchorrhoea related to lung cancer.
Antitussives should ideally be avoided in patients with productive patients but may be used if sleep is disturbed by coughing.

If the patient is at the terminal stages and is too weak to cough

Consider the following medication

- Antimuscaranic drugs: e.g., iptratropium (nebulised), amitriptyline 10–50 mg at night; gycopyrronium (SC),0.2-0.4 mg initially, then 1.2-2 .4 mg by SC infusion per 24 hours (also avoids sedative effect of hyoscine hydrobromide); hyoscine hydrobromide (SC) 0.2-0.4 mg every 4 hours; hyoscine butylbromide (SC)20 mg initially, then 40 mg SC per 24 hours (this avoids the sedative effects of hyoscine hydrobromide)

- Corticosteroids: dexamethasone 8 mg orally daily for 5 days, reducing to 4 mg daily as maintenance, may be a useful adjunct in patients with lymphangitis carcinomatosis or upper airways compression

- Cough suppressants (refer below)

Suppressing Cough

The following options are available to suppress cough:

- Reduce pharyngeal stimulation using a simple linctus 10 mL every 2-4 hours.

- Central suppression of the cough reflex using narcotic medications such as codeine phosphate 30-60 mg every 4 hours P.O. (or as codeine linctus 15 mg/5ml at a dose of 5-10 ml QDS)

- Morphine 2-20 mg every 4 hours. Initial dose should be 5 mg every 4 hourly P.O. If already taking morphine, try a 25 – 50% increase in dose and titrate against drowsiness. The same applies to using alternative opiates to morphine with oxycodone and hydromorphone being the most accessible options in appropriate dosage.

- Methadone: some authorities advocate methadone as a better opiate for cough. Commence 2. 5-5 mg every 6 hours for 24 hours, then reduce dose to 12-hourly (this can be added to the

patient's other opiate regimen, although drowsiness and a long sleep has been reported with the first dose). The dose can be escalated according to effect but should only be changed at weekly intervals in 25-50% steps Excessive drowsiness on methadone will take 24 hours to settle and doses should be omitted for this time then recommenced as half the dose.

- A trial of gabapentin (doses up to 1800 mg/day) may be tried in adults with chronic refractory cough
  Paroxetine 5-20 mg has been reported to be very effective though its site of action is unknown

- Local anaesthetic: blockade of cough receptors may be used in patients whose symptoms persist despite central suppression. Options include: lignocaine 0.2%, 5 mL by nebulizer every 4-12 hours or bupivacaine 0.25%, 5 mL by nebulizer every 4-12 hours. Only one or two doses a day may be required when effective. Mechanical cough receptors at the level of the carina will be blocked with standard nebuliser. If symptom control is not achieved, an ultrasonic nebuliser can produce a smaller particle size that will additionally block chemical cough receptors in bronchioles. Patients should be advised not to eat or drink for an hour following the treatment as they may be at risk of aspiration.

References

1. Cole R, Formby F. Symptom control in palliative care. Current Therapeutics. 2000 Sep;41(9 Suppl).
2. Lanarkshire NH. Palliative Care Guidelines. (2009)
3. Watson M et al. *Oxford Handbook of Palliative Care* Oxford University Press

CHAPTER 8

Neurological Symptoms

Delirium among palliative care patients

Introduction

Delirium is a neurocognitive syndrome arising from acute global brain dysfunction. Nearly 42%of the inpatients in palliative care suffer from this syndrome.
Delirium causes changes in cognition over a short period of time (hours to days). Patient may have reduced level of consciousness, awareness with reduced ability to focus, sustain or shift attention with a fluctuating course. Dementia and stroke are known predisposing conditions for developing delirium.

Delirium can affect sleep wake pattern, ability to do activities of daily living, communication (incoherent), attention and concentration, perceptions (hallucinations and illusions) and memory. Acute changes in behaviour with agitation and confusion in the late evening (sun downing) may indicate early delirium.

Three categories of delirium have been identified.

1. Hyperactive (symptoms include agitation, psychosis and emotional lability)
2. Hypoactive (symptoms include sluggishness, lethargy, confusion, and an absence of disruptive or bizarre behaviour)
3. Mixed (include both hyperactive and hypoactive symptoms)

Mixed delirium is the commonest form where patient can fluctuate to and fro from hyperactive to hypoactive states. Hypoactive delirium is more difficult to recognise and is characterised by drowsiness and inactivity with confusion.

Delirium could affect optimal management of other symptoms due to patient's inability to report them.

Terminal delirium

Terminal delirium is delirium occurring within the final 24 to 48 hours of life. Many terminally ill patients with cancer, chronic obstructive pulmonary disease (COPD), end-stage renal disease, heart failure, and other serious life-threatening diseases that lead to global cerebral dysfunction with no reversible underlying aetiology, manifest as delirium which is the final common complication that precedes death. Terminal delirium too can be of hypoactive, hyperactive and mixed forms.
Terminal delirium is common at the end of life. Approximately 25 - 85% of terminally ill patients experience terminal delirium during the last hours to days.
It may cause family and caregiver stress and have an impact on bereavement process.

Assessment

Comprehensive assessment is the key to effective management of delirium. This includes interview, physical assessment, medication review, medical and surgical review, psychosocial review, review of physical environment and focused diagnostic investigations.

Management

It is very important to recognise delirium clinically, since it is largely under recognized in many clinical settings. Non pharmacological measures must be employed in all cases of delirium. Identifying precipitants and managing them is the key in the management of delirium.

Non pharmacological management

- Explain and reassure the family that symptoms of delirium are caused by illness, they are not within patient's control and that patient is not insane.
- Instruct the family to be gentle and not to argue with the patient.
- Encourage family to be present in a calming way.
- Provide a calm and quiet environment, help the patient to reorient in time, place and person (visible clock, calendar, well known familiar objects). Presence of a well-known family member is preferred; provide a well-lit (even during night) environment
- Minimise the number of visitors, staff changes and room changes.
- Discontinue unnecessary drugs and consider prolonging dose intervals for necessary drugs.
- Provide spectacles and auditory aids if the patient needs them.
- Avoid physical restraints and other impediments to ambulation.
- Avoid catheterisation other than for urinary retention. Encourage activity if physically able. Misinterpreting pain as the cause of delirium and escalating opioids may potentially aggravate symptoms and cause opioid neurotoxicity.
- Correct any reversible factors.

Box 1: Precipitants or Reversible causes of delirium

- Drugs (e.g. anticholinergics, opioids, benzodiazepines, steroids, antihistamines, chemotherapy)
- Infections (urinary, pneumonia, other sepsis)
- Constipation
- Drug withdrawal or toxicity
- Dehydration
- Electrolyte imbalance
- Endocrine dysfunction (thyroid, adrenal)
- Uraemia
- Alcohol withdrawal
- Under treated pain
- Sleep deprivation
- Hypoglycaemia
- Hypoxia
- Hyperthermia

Pharmacological management

- Review medications. Consider opioid rotation to reverse opioid neurotoxicity.

- Withdraw anticholinergic agents.

- Benzodiazepines may paradoxically excite some patients and should be avoided unless the source of delirium is alcohol, sedative drug withdrawal or severe agitation resistant to neuroleptics.

- If brain metastases are suspected, consider trial of corticosteroids (dexamethasone orally in the morning).

- Antipsychotics are best avoided for mild delirium. There is no place for prophylactic antipsychotics or continuous treatment with antipsychotics in delirium.

- Antipsychotics can be used only if non pharmacological measures are ineffective. Distressing hallucinations or agitated delirium are the other indications. These agents have been associated with a higher risk of mortality and possibly stroke when used in patients with dementia. Hence they should be used with optimum dosage for minimum possible duration and consider withdrawal once it is no more indicated.

    - Haloperidol remains the drug of preferred choice. Oral haloperidol is started with a low dose (0.5 to1 mg) and may be escalated to a maximum of 5 mg per day. Route of administration could be oral, intramuscular (i/m) or intravenous (i/v). Onset of action may be as soon as 5 to 20 minutes after intravenous administration and longer with the IM or oral route. An immediate response is not expected. Intravenous haloperidol has been associated with clinically significant QT prolongation requiring additional precautions with its use.
    - The newer atypical antipsychotic agents quetiapine, risperidone, and olanzapine have fewer side effects in other clinical settings and in small studies they appear to have

- similar efficacy to haloperidol. Risperidone 0.5-1 mg PO b. d, olanzapine 2.5-15 mg P O daily, quetiapine 50-100 mg PO b. d.
- If patient is having parkinson's disease or dementia with Lewy bodies (DLB), antipsychotics should be avoided.
- Levomepromazine is a phenothiazine neuroleptic used for analgesic, sedative, anti-emetic action and for delirium. Levomepromazine is frequently prescribed and valued worldwide in palliative care medicine for its multimodal action to treat intractable nausea or vomiting and for severe delirium/agitation in the last days of life. It can be prescribed orally or via subcutaneous syringe drivers in combination with opioid analgesics such as hydromorphone. Starting dose in syringe driver is 25 mg /24 hours. Breakthrough doses of 12.5 mg SC hourly can be given as required.

- Benzodiazepines should be avoided as much as possible in delirium since they can worsen confusion and sedation. Indications to use them are when you require sedation and in alcohol withdrawal or when antipsychotic drugs are contraindicated. Lorazepam 0.5-2 mg SC 4-6 hourly p.r.n or midazolam 2.5 – 5 mg SC hourly p.r.n or chlorpromazine 25 – 50 mg SC 6-8 hourly p.r.n.

Seizures among palliative care patients

Introduction

Seizures (generalised or partial) occur in 10-15% of palliative care patients most often due to primary or secondary brain tumours,

cerebrovascular disease, epilepsy, or biochemical abnormalities (e.g. low sodium, hypercalcaemia and /or uraemia).

Assessment

- Exclude other causes of loss of consciousness or abnormal limb/ facial movement. (e.g. vasovagal attacks, postural hypotension, arrhythmia, hypoglycaemia and alcohol).
- Find out if the patient has had previous epilepsy, known cerebral disease.
- Is there a problem with usual antiepileptic drug therapy? – Unable to take oral medication, drug interactions.

Management

- Primary prophylaxis with anticonvulsants is not recommended for patients with brain tumours where patient has not had a seizure.
- Patients should be given dexamethasone before, during and immediately after radiotherapy to prevent oedema secondary to acute radiation toxicity which can provoke seizures.

Acute seizure management

- Put patient in the recovery position and administer oxygen. Ensure safety and protect airway.
- Do a capillary blood sugar - if hypoglycaemic give thiamine 100 mg IV and IV 50% dextrose 50 ml

- If seizure does not resolve consider slow i/v diazepam 5- 10 mg, lorazepam 4 mg or clonazepam 1 mg.
- Buccal midazolam 10 mg or diazepam rectal (or via stoma) 10-30 mg also could be used.
- Correct electrolyte abnormalities.
- Consider discontinuing proconvulsive medications (haloperidol, tramadol).
- Start regular antiepileptic medication.

Follow up- seizure management in non-dying (early palliative) patient

- Consider investigating for reversible causes.
- Review and optimise anti-epileptic mediations.
- Exclude drug interactions reducing anti-epileptic efficacy.
- Seek advice from local neurology team if needed.

Follow up- seizure management in last days of life

- See last days of life (midazolam SC infusion; sodium valproate and levetiracetam can be given as SC route)

Insomnia among Palliative patients

Introduction

Insomnia meaning impaired sleep, includes difficulties in either initiating or maintaining sleep. Patients may experience sleep as non-restorative and unrefreshing, despite having the suitable environment for sleep. Prevalence of insomnia is over 60% among

palliative patients. Insomnia leads to a negative impact on quality of life and functional status of the patient.

In the context of palliative care, insomnia often coexists with pain, depression, and anxiety where, presence of one, often exacerbates another, contributing to a drop in quality of life.

Approach to treatment of insomnia should be individualized depending on their functional status and stage in the disease trajectory where patient is currently in.

Furthermore, patient's insomnia can significantly impact on his or her caregiver's sleep quality and their overall quality of life. Impaired sleep among caregivers increases irritability, depression, anger, and guilt leading to decreases in overall ability to provide care.

Factors which may contribute to insomnia

1. **Physical symptoms** – e.g.; pain, breathlessness, cough, hiccup.
2. **Psychiatric illness** – anxiety and depression can contribute to insomnia.
3. **Environmental factors** – sound (music, conversations), light (computer screen, television, bright illumination of room), hospital (ward activities, night round, night medications, waking patient for assessments).
4. **Physical condition of the patient** – the more immobile (chair or bed bound) the patient, the more insomnia they will experience.
5. **Emotional distress** – palliative patients may experience fear, anger, concerns over approaching end of life.
6. **Medication side effects** – medications with stimulant properties e.g. Opioids, steroids, beta agonists, many antidepressants and psychostimulants.

7. **Underlying medical conditions** – underlying advanced disease itself may cause insomnia. e.g. cancer, COPD, Parkinson's disease

Management of insomnia

- Deal with reverse contributory factors- (e.g., pain control, suppression of cough, treatment for depression).

- If pharmacotherapy is indicated for other clinical problems, consider an agent with somnolence as a side effect. (e.g. depression- mirtazapine).

- Assess where in the disease trajectory the patient is in. Patients in early phase in disease trajectory are likely to tolerate treatments similar to medically healthy individuals. However, patients towards terminal and end of life phase, may be more susceptible to side effects due to drugs- drug interactions and organ impairments.

Management includes 'pharmacological' as well as 'non-pharmacological' interventions.

Non-pharmacological interventions

Environment - Keep the room well ventilated. Make it a quiet place. Have optimum temperature (60 - 67° Fahrenheit) for sleep. Bright light from lamps, cell phone and TV screens can make asleep. Consider using blackout curtains, eye shades, ear plugs, "white noise" machines, humidifiers, fans and other devices that can make the bedroom more relaxing.

Lifestyle modifications – reduce or avoid day time naps (maximum 30 min), caffeine or nicotine at bed time. Avoid large meals or excessive fluids (fatty, fried meals, spicy dishes, citrus fruits, and carbonated drinks painful heartburn or regurgitation may disrupt sleep).

Promote physical comfort — prevent discomfort from beds; use comfortable mattresses e.g. foam 'egg crate' or 'memory foam' mattress toppers.

Encourage healthy sleep-wake cycles — increased exercise and regular exposure to natural daylight for at least an hour every morning has been shown to restore sleep cycles among patients with Alzheimer's disease.

Keep with bedtime routines- if patient has been used to regular nightly warm shower or baths, reading a book, or light stretches, a snack prior to bed, then this routine should be maintained as much as possible. Try an avoid emotionally upsetting conversations before sleep.

Minimize disruptions — minimize disruptions of sleep by staff. Avoid nursing, dosing, fluids, nutrition, hydration, and visitors at night.

Spiritual distress – This may contribute to insomnia needing attention.

Pharmacological management

Pharmacotherapy for insomnia includes *management of conditions contributing to insomnia* (e.g. adequate pain relief at night), *withdrawal of psychostimulants* including steroids and *medications to induce sleep*.

Medications to induce sleep

Palliative patients are more likely to suffer from adverse effects of sleep medications. Hence medications to aid sleep should be used only after employing non pharmacological methods. Use of medications should be individualized based on the patient's current status, prognosis, goals, and underlying medical conditions.

Prescription medications

Benzodiazepines — This is the most prescribed class of medications for insomnia among non-palliative patients. Since benzodiazepines are associated with adverse effects, one should be careful in using them in palliative patients.

Among adverse effects are; rapid development of tolerance leading to return of insomnia, withdrawal symptoms on discontinuation, potential for cognitive impairment and falls, concern for impaired respiratory function in patients with COPD and potential for increased central nervous system depression, when used in combination with opioids.

Non-benzodiazepine hypnotics — (e.g. zolpidem, zopiclone). They are approved for insomnia in the general population. They may be safer than benzodiazepines for patients with chronic respiratory issues (eg, COPD). This class is associated with a risk of adverse effects e.g. increased risk of falls with zolpidem.

Atypical antidepressants — Mirtazapine usually indicated for major depression, generalized anxiety disorder, and tension-type headaches is associated with sedative side effects (at least at doses of 7.5 to 15 mg), hence may be useful for the treatment of the depressed or anxious patient also experiencing insomnia.

Sedating antidepressants — Doxepin is approved for the treatment of insomnia, although it has significant side effects, including dizziness, dry mouth, blurred vision, constipation, and urinary retention which at a low doses (ie, 3 to 6 mg) is not usually seen.

Selective melatonin receptor agonists — Ramelteon, a selective melatonin receptor agonist, is approved for the treatment of insomnia in the United States and Japan. It is metabolized primarily through the CYP450 1A2 pathway, hence should not be co-administered with other potent inhibitors of this pathway, such as ciprofloxacin and fluvoxamine.

Over-the-counter agents

Diphenhydramine — Diphenhydramine is an over-the-counter antihistamine with sedating properties. Because of the side effects, primarily related to the anticholinergic action (eg, dry mouth, decreased cognitive function, delirium), it is not preferred for treatment of insomnia.

Melatonin — Melatonin is a neurohormone secreted by the pineal gland that can assist with maintaining sleep-wake cycle. It is a widely available over-the-counter agent for insomnia. Melatonin has been modestly effective in reducing initial sleep latency and frequent night time or early morning awakenings for patients receiving palliative care.

Comorbid conditions

Older adult patients often have multiple comorbid medical conditions that can contribute to sleep disturbances. Patients with **dementia** are at an increased risk for experiencing insomnia as a potential symptom (e.g. sun downing, agitation, or other delirium). Management of insomnia in patients with dementia should focus on prevention (multicomponent preventative strategies) and treatment of delirium which is common among them.

References

1. NHS Lancashire Guidelines
2. NHS northern England Clinical network Palliative care and end of life care guidelines for Symptom control
3. Roger Cole. Symptom control for Palliative care 5th edition
4. Scottish Palliative care guidelines NHS
5. Uptodate https://www.uptodate.com overview of insomnia in palliative care

CHAPTER 9

Urinary Symptoms

Introduction

Urinary symptoms are common in the elderly. It could be partly due to age related benign prostatic obstruction and related complications in men. Incidence of prostate cancer also increases with the advancing age. Diabetic patients are at a higher risk of frequent urinary tract infections (UTIs) and longstanding diabetics are predisposed to lower urinary tract dysfunction, too. Similar symptoms in females are commonly due to post-menopausal oestrogen deficiency and related uro-genital atrophy, urethral stenosis and lower urinary tract dysfunction. Patients who are on indwelling urinary catheters frequently encounter a different set of problems related to catheters and catheter care. Wider knowledge and understating of this background is the key to success in palliating those who are presenting with urinary symptoms.

Objectives

- To identify common urinary symptoms in the elderly.
- To establish a standard patient evaluation protocol.
- To outline a treatment plan for common conditions in both males and females.

- To prevent doing more harm and avoiding some of the malpractices in patient management

Common urological symptoms/problems for palliation

- Dysuria
- LUTS
- Nocturia
- Urgency and urgency urinary incontinence
- Recurrent UTIs
- Long term catheters and catheter care
- Pericatheter leak and bladder spasms
- Ureteric stents and stent symptoms

Management priorities- General principles

- Exclude UTIs
- Differentiate between UTIs and asymptomatic bacteriuria
- Better glycaemic control
- Life style modifications
- Identify any underlying urinary tract conditions/ diseases
- Appropriate pharmacological treatment avoiding unacceptable adverse effects of treatment
- Proper catheter care (for those with indwelling catheters)
- Do not hesitate to seek expert opinion when in doubt

Dysuria

Complaint of pain, burning or other discomfort during voiding. Discomfort may be intrinsic to the lower urinary tract (e.g. bladder or urethra), external or referred from other adjacent similarly innervated structures e.g. lower ureter.

Causes of dysuria

- Urinary tract infections (cystitis, urethritis)
- Prostatic obstruction (benign prostatic obstruction/ prostate cancer)
- Prostatitis
- Urethral strictures
- Urethral stenosis (in females)
- Vaginal infections
- Sexually transmitted infections (STIs)
- Recent urinary tract instrumentation/ catheterization
- Inflammation (non-specific)/ irritation of the lower urinary tract (urethra/ bladder)

Diagnostic evaluation

Urinary tract infection being the leading cause of dysuria, initial evaluation should be targeted at identification of the same. Depending on the associated symptoms and signs likely cause should be identified

Initial investigations include urinalysis (UFR, Urine for culture and ABST), inflammatory markers (WBC, CRP), however selected patients may need further evaluation with USS KUB with pre and post-void residual volumes and urinary flow rate (uroflowmetry) assessment and inputs form a urologist if dysuria persists.

Treatment

Adequate fluid intake.

Lifestyle modifications. (regular bladder emptying, diet, etc.)

Treatment of UTI with antibiotics (initially empirical, later guided by the culture ABST) for an adequate duration (5- 7 days, depending on the response). Preferred first line agents include nitrofurantioin, cotrimoazole, nalidixic acid, trimethoprim, cephalexin, cefuroxime, etc. Quninalones (ciprofloxacin, norfloxacin) are best avoided as first line antibiotics for lower urinary tract infections.

Better glycaemic control in diabetics.

Urinary alkalization with potassium citrate (1080mg twice a day) may be helpful, if urinary acidity is high

Recurrent UTIs

When confirmed UTIs occur in a frequency of two or more episodes over 6 months or three or more episodes over one year.

Further evaluation should be targeted at identification of any underlying cause (diabetes, urinary stones, poor bladder emptying associated with bladder out flow tract obstruction/ bladder dysfunction).

Asymptomatic bacteriuria

Positive urinary cultures without any symptoms of UTIs or without elevated inflammatory markers in blood (CRP/ WBC) may indicate asymptomatic bacteriuria (due to colonization) rather than infection, especially in patients on indwelling catheters, therefore antibiotic therapy is not recommended. Overtreatment of asymptomatic bateriuria could lead to adverse outcomes such as higher incidence of antibiotic resistance.

Lower urinary tract symptoms (LUTS)

According to the International Continence Society (ICS), they can be broadly classified into 3 categories: voiding, storage, and post-micturition.

Storage	Voiding	Post-micturition
• Increased day time Frequency • Nocturia • Urgency • Urgency urinary incontinence • IIry nocturnal enuresis	• Hesitancy • Poor stream • Straining to void • Intermittency • Terminal dribble	• Feeling of incomplete emptying • Post-micturition dribble

LUTS could be due to,

- Bladder outflow tract obstruction (BOO)
- Bladder irritation/ dysfunction
- Polyuria

Common causes of BOO in men include benign prostatic obstruction.

Diagnostic evaluation

Aimed at establishing the underlying cause. USS KUB (P) with pre and post-void residual volume + IPP and Uroflowmetry are investigations of choice. Bladder diary is useful in selected patients especially bladder cause or polyuria is suspected. In BOO or bladder dysfunction, possible complications should be looked for.

Treatment

Life style modification:

Reducing fluid intake after 6pm, reducing the intake of tea, coffee, fizzy drinks etc.

Pharmacological therapy:

One alpha blockers (1αA blockers such as tamsulosin, terazosin are superior to nonselctive alpha 1 blockers such as prazosin).

5 alpha reductase inhibitors (finasteride, dutasteride) are combined with alpha blockers only for larger prostates more than 30-40cc, however commencing 5 alpha reductase inhibitors should be differed in patients with elevated serum PSA or awaiting PSA

assessment until assessment is complete and a cause for elevated PSA is established (possibility of prostate cancer is excluded).

Anticholinergics have a place in the presence of bothersome storage symptoms provided bladder emptying is satisfactory as confirmed by ultrasonography.

Further management:

Poor responders to initial therapy should be referred for Urosurgical opinion and further management.

Nocturia

This is the complaint that the patient has to wake at night once or more in order to void. This could commonly be in association with other lower urinary tract symptoms, but could be the only symptom at the time. Nocturia is a widespread condition that can negatively impact quality of sleep and overall health of the affected individual. This condition is multifactorial in nature and is best approached through the analysis of frequency volume charts/ bladder diary.

If nocturia is persistent and being the main symptom, the assessment should be aimed at recognizing nocturnal polyuria after excluding excessive intake of fluid.

Nocturnal polyuria is defined in an age-dependent manner as nocturnal output greater than 20% of the daily total in the young and greater than 33% of the daily total in the elderly. Here, daily total urine output generally remains unchanged and nocturnal urine volume is the total volume of urine voided during the night, including the first morning void.

Treatment

Behavioral modification techniques are appropriate first-line treatment for patients with nocturia, regardless of the aetiology. These include modifying global and evening fluid intake, restricting the consumption of foods that promote diuresis, and improving patient understanding of the physiology of storing and voiding urine

Diabetic patients should maintain their glycaemic control within the normal range.

In the case of nocturnal polyuria any relevant systemic disease, such as congestive cardiac failure and obstructive sleep apnoea should be identified and addressed.

In patients taking diuretics, the administration of these medications 6 hours prior to bedtime can reduce night-time frequency and the percentage of night-time voided volume

When peripheral oedema is a concern, simple evening leg elevation or compression stockings can redistribute third space fluid

Desmopressin can be used to treat severe cases or cases resistant to general measures and this could be under strict medical guidance and supervision.

Urgency and urgency urinary incontinence

Urgency is the sudden compelling desire to pass urine which is difficult to defer. Involuntary leakage accompanied by or immediately preceded by urgency is known as urgency urinary incontinence (UUI).

Urgency and UUI can occur as a result of,

primary bladder dysfunction (neurogenic/ idiopathic), bladder oversensitivity or irritation (due to cystitis, bladder stones, bladder tumours, post-irradiation etc.)

secondary to bladder outflow tract obstruction (secondary overactivity)

Treatment

Identification of any underlying cause and treatment of the cause should be the primary goal.

Lifestyle modifications such as reducing intake/avoidance of specific beverages are known to irritate the bladder such as tea, coffee, fizzy drinks etc. and shifting to decaffeinated beverages when appropriate, is practiced as a general measure.

If no correctable underlying cause could be identified, symptomatic treatment includes use of anticholinergics (oxybutynin, tolterodine, solifenacin, etc.), provided bladder emptying is satisfactory.

Urinary catheters and catheter care

Urinary catheters are used to artificially empty the bladder. This could be achieved by indwelling catheters or by performing intermittent catheterization.

Indications for indwelling catheters

- For monitoring of hourly UOP in critically ill
- Prolonged surgical procedures/ prolonged anaesthesia
- Acute urinary retention
- High-pressure chronic urinary retention
- Following certain urosurgical procedures of the lower urinary tract (transurethral resection of prostate, open prostatectomy, radical prostatectomy, open bladder surgeries, transurethral resection of bladder tumour, urethral surgeries etc.)
- Severe bladder outflow tract obstruction in surgically unfit patients
- Urinary incontinence with failed other treatment strategies/ in patients unfit for interventions

Urinary catheterization- Key steps

- Cleaning of genitalia: 10% povidone iodine (unless allergic to povidone iodine)
- Catheter type: Latex (short-term use), silicon (for long-term use)
- Catheter size: 14Fr for females, 16Fr for males
- Aseptic non-touched technique
- Local anaesthetic gel instilled in to the urethra
- Atraumatic insertion
- Inflating the balloon: once the catheter is fully advanced, with distilled water, minimum volume required (usually 10 ml)
- Withdrawal of the excess length of the catheter and securing without any tension and pressure on the external urethral meatus
- Replacement of the retracted prepuce in uncircumcised males
- Recording: catheterization date & time, retained volume of urine, urine colour, any difficulty encountered etc.
- Post-catheterization care plan including planed date for catheter removal/ revision

Catheter care advice

Adequate fluid intake and hydration to maintain urine colourless/ lighter colour

Keeping the external genitalia and catheter clean (washing with soap and water)

Catheter bag at a dependent position

Avoiding kinking of the catheter/ catheter tubing

Emptying the bag when half filled

Changing the catheter bag weekly is the best practice (extra-bags should be available)

Regular changing of the catheter (latex catheter- every 4 weeks, silicon catheter- every 3 months)

Issues encountered with indwelling catheters and practical approach to problem solving

- **Pericatheter leak (catheter by-passing) and/ or bladder spasms**

Exclude catheter block

Smaller catheter size (If a larger size is used)

Reduce the catheter balloon to minimum (10 ml or less)

Suppression of bladder spasms (detrusor overactivity) with anticholinergics (oxybutynin, tolterodine, solifenacin, etc.)

- **Catheter induced haematuria**

Increase fluid intake

Avoid catheter traction (secure catheter in position)

Exclude UTIs (urine culture and ABST) and general bleeding tendencies; if clinically suggestive/ indicated

If persistent or recurrent haematuria/ any clots leading catheter blockage- seek urological advice, as further evaluation is needed to look for a cause.

- **Debris/ sediments in urine**

Debris/ sediments causing cloudy urine is inevitable and longer the patient has been on an indwelling catheter commoner the problem. This does not indicate urinary tract infection/ pus in urine in many occasions. If it blocks the catheter, catheter should be flushed with 0.9% NaCl to clear the blockage. If catheter blockage is frequent Urologist's input is needed for cystoscopy and bladder wash outs.

- **Positive urine cultures**

It's common to have catheter colonization and positive cultures, therefore treatment with antibiotics are not indicated routinely unless symptomatic (symptoms of UTIs) with raised inflammatory

markers. Regular urinalysis in asymptomatic patients who are on indwelling catheters is generally not recommended.

If UTI is suspected a urine sample for culture and ABST should be properly collected in a catheterized patient (not from catheter bag).

Ureteric stents and stents related symptoms

Patients on ureteric stents may experience stent related symptoms. Common symptoms include dysuria, frequency, urgency, intermittent haematuria, end stream pelvic pain and vague loin discomfort during voiding. These symptoms are also seen with urinary tract infections (UTIs) and at times it's extremely difficult to differentiate between two. Urine full report may also show red cells and pus cells in both conditions and therefore no much of a value. When there is a suspicion of an associated urinary tract infection urine culture and inflammatory markers should be performed.

Management of stent symptoms

- Exclude a UTI
- Increased oral intake of fluid
- Pharmacotherapy: (Tamsulosin/ Toterodine ER)
- Early removal of the stent (If this is appropriate)

References

1. Abrams P, Cardozo L, Fall M, et al. The standardization of terminology of lower urinary tract function. Report from the standardization subcommittee of the International Continence Society. Neurourol Urodyn. 2002;21:167–178.
2. D'ancona C, Haylen B, et al. The International Continence Society (ICS) report on the terminology for adult male lower urinary tract and pelvic floor symptoms and dysfunction. Neurourol Urodyn. 2019;1–45.
3. European Association of Urology Guidelines 2019.
4. Fine ND, Weiss JP and Wein AJ. Nocturia: consequences, classification, and management [version 1; referees: 3 approved] F1000 Research 2017, 6(F1000 Faculty Rev):1627 (doi: 10.12688/ f1000research.11979.1).
5. Management of urethral catheter. British Association of Urological Surgeons, leaflet no 16/004. April 2017. http://www.baus.org.uk/_userfiles/pages/files/Patients/Leaflets/Catheter.pdf
6. Miyaoka R, Monga M. Ureteral stent discomfort: Etiology and management. Indian J Urol. 2009 Oct-Dec; 25(4): 455–460.

CHAPTER 10

Symptoms Related to Skin and Mucosal Membranes

Pruritus

Pruritus (itch) is the unpleasant sensation that provokes an urge to scratch. The International Forum for the Study of Itch (IFSI) proposes a two-tier classification system for pruritus based on whether the aetiology is known or not. When the aetiology is known, pruritus is further divided into dermatological, systemic, neurologic, psychogenic, and mixed categories

The common aetiologies of pruritus in the palliative setting are chronic renal failure, liver disease, hematologic (especially lymphoproliferative) disorders and drugs (especially opioids).

Mainstay of treatment is eradication of primary cause, which is not an option in majority of patients. The first line treatment consists of local applications.

Non -pharmacological and topical treatment:

Presence of dry skin often exacerbates pruritus. Prevention of dry skin should be attempted in all patients with pruritus by the following measures;

- Minimize application of water (especially hot water) and soap products.
- Regularly lubricate the skin with emollients specially after bathing.
- Maintain a cool humidified environment.
- Advise to wear non-irritating loose clothes, avoid skin irritants such as perfumes.
- Locally applied emollients, antipruritic and protective agents

- Calamine oil lotion - apply 4 times daily, and as required (**calamine creams and ointments will dry the skin further**).
- Topical cooling agents such as 1% methanol lotion and/or 0.5% camphor lotion
- Examples of common over-the-counter preparations include lidocaine cream (2.5%), lidocaine patch (5%), lidocaine-menthol cream, lidocaine-menthol patch, mixture of lidocaine 2.5% and prilocaine 2.5% cream (EMLA), and pramoxine 1% lotion
- Paraffin preparations applied 3-4 times a day and as required.
- Sorboline (Sorbone cream,Hydroderm) applied 3-4 times daily or as required
- Use of topical corticosteroids are limited to localized inflammatory pathologies.

Pharmacological (systemic) management:

When the aetiology of pruritus is uncertain following systemic therapies can be initiated empirically.

- Antidepressants
  - (oral) sertraline 25 to 75 mg daily
  - (oral) paroxetine 20mg in the morning
  - (oral) mirtazapine 7.5 to 30 mg at bedtime (sedative, benefits in lower doses).

- Anticonvulsants
  - (oral) gabapentin 30-3600mg in divided doses
  - (oral) pregabalin 75 -300mg in divided doses
- Glucocorticoids may be considered if pruritus is acute, severe, and remains refractory.

    - (oral)prednisone 30 mg/day
    - (oral/ subcutaneous) dexamethasone 4 to 8 mg/day
- Effectiveness of antihistamines in palliative settings is limited. Sedating antihistamines are prescribed primarily due to their calming effect.
    - (oral) promethazine 10mg to 25mg up to 3 times per day

Common clinical syndromes associated with pruritus' in palliative patients are as follows

Cause	**Clinical manifestation**	**Mechanism**	**Management**
Uremia	Generalized, intermittent or continuous	▪ Skin atrophy and dryness ▪ Secondary hyperparathyroidism ▪ Accumulation of pruritogenic metabolites ▪ Abnormal mast-cell proliferation in skin	Emollient creams/lotions: as in dry skin with or without night sedation ondansetron: 4-8mg orally or s.c every 8hours naltrexone : 12.5 - 100mg once daily (Should **not** be given to patients taking opioid analgesics) mirtazapine: 7.5-15mg at bed time sertraline 25mg to 50mg paroxetine: 5-10mg orally daily

			gabapentin 100mg after each haemodialysis session
Cholestatic pruritus (primary and secondary liver disease/malignancy)	Generalized but worse on palms and soles	• Altered opioidergic transmission • Increased serotonin release • No correlation between bile acid levels and degree of pruritus	paroxetine 10-20mg orally ondansetron 4-8 mg orally or subcutaneously daily. rifampicin 75mg once daily can increase up to 150-300mg bd sertraline 25 to 50 mg/day mirtazapine 15 to 30 mg/day
Malignancy related ▪ Hematologic al ▪ Solid tumour	Aquagenic pruritus in lymphoproliferative disorders	Cytokine imbalance in response to tumor-specific antigens	gabapentin 30-3600mg pregabalin 75 -300mg paroxetine (5 to 20 mg/day), sertraline (25 to 50 mg) fluvoxamine (25 to 100 mg/day) mirtazapine (15 to 30 mg/day) Glucocorticoids, such as prednisone (30 to 40 mg) tapered off over three weeks has been reported to be helpful in treating pruritus in lymphoma patients not responsive to above therapies

Drugs • Opioids	With systemic opioids, pruritus is generalized and may be accompanied with wheal/flare response Common in the first week of starting opioid analgesic medications	Centrally mediated by mu-opioid receptor activation of serotonin pathways	Opioids rotation Use of opioid antagonists such as naloxone and naltrexone may result in reversal of analgesic effects. gabapentin 30-3600mg pregabalin 75 -300mg

Mouth care

Mouth care is a frequently neglected but very important aspect in palliative care. It should be a part of daily routine and it maintains self-esteem, comfort, and the person's ability to communicate, socialize, and enjoy food and drinks.

Examination

Remove dentures before examining the mouth or performing routine mouth care. Thoroughly examine the mouth using a torch. Check whether the oral mucosa is clean.

General mouth care measures:

Oral care should be provided at least four times daily. Some patients may need more frequent care.

- Maintain fluid intake with frequent, small drinks, if patient still swallows
- Apply water-based gel to dry lips after oral care.

    - Avoid lubricating cracked lips with a water-based product as it would be painful. Keep mouth and lips clean, moist, and intact by removal of plaque and debris.

- Reduce intake of sugary foods and drinks between meals

    - If patient awake, salivary flow can be improved with pineapple pieces or crushed ice.

Dry mouth (xerostomia) and coated mouth

- Review and withdraw medications which cause dryness of mucosa.

- Gently remove coatings, debris and plaque from soft tissues, lips and mucosa with soft toothbrush or mouth swab.

    - Be careful in removing plaques, otherwise it will cause pain, ulcerations and bleeding, which will ultimately predispose to infections.

Stomatitis and Mucositis

Oral mucositis present particularly in patients receiving chemotherapy or radiotherapy. It is a condition characterized by pain and inflammation of the mucous membrane which may present as painful mouth ulceration affecting any or all intra-oral surfaces.

Management

- Avoiding dry, hot or acidic meals (substitute with cold, soft meals)

- Chlorhexidine gluconate 0.2% mouthwash can be considered when pain limits other mouth care

methods.10ml used twice daily may be useful to inhibit plaque formation in patients unable to tolerate other mouth care measures. Dilute 1:1 with water if it stings. Alcohol-free preparations are available.

- Local anaesthetic preparations can be used as PRN
    - Recommended doses

Lignocaine gel/ viscous 2% 5ml-10ml 4 hourly PRN

- A short course of corticosteroids can be used for radiation induced mucositis.
    - Recommended doses

(Oral/subcutaneous) Dexamethasone 4mg daily in the morning for 2 weeks.

- Patient may need systemic analgesia to control pain.
    - Refer to chapter on pain management

Fungal infections

The most common types are candidiasis, denture stomatitis and angular cheilitis. Systemic antifungal treatment is not desirable if patient approaching terminal phase.

Management plan:

- Topical preparations
    - miconazole 2% oral gel should be considered for treating angular cheilitis (soreness, redness and fissures at corners of mouth). Apply 2.5ml topically four times daily retained near lesions before swallowing.

- Nystatin 100 000 units lozenges
    - Apply crushed tablets topically four times daily.
- Oral clotrimazole 1% (candid) mouth paint and daktarin gel can be used as alternative topical agents

- Systemic antifungal agents
    - fluconazole (capsules or suspension) 50mg daily for 7 days.

Excessive drooling

This condition occurs due to impaired swallowing of saliva rather than excessive saliva production. Common in patients with Neurodegenerative disorders, such as motor neuron disease, Parkinson's disease, multiple sclerosis.

Management

- Positional change of the patient (regular vigorous suctioning is poorly tolerated by most patients)
- Speech and language therapy around swallowing techniques.
- Anticholinergic agents can be used to reduce production of secretions.

Recommended doses

- (subcutaneous) hyoscine butylbromide 20 mg four hourly (up to a maximum daily dose of 120 mg per

day). Oral route only effective in gastrointestinal pathologies due to limited bioavailability.

- (subcutaneous) glycopyrrolate 0.2 mg four hourly (up to a maximum daily dose of 1.2 mg per day).
- atropine 1% eye drops 4 drops (sublingually) 4 hourly PRN.

Above anticholinergic medications may exacerbate dry mouth causing thickened secretions which may be more difficult to clear.

References

1. Desai NS, Poindexter GB, Monthrope YM, et al. A pilot quality-of-life instrument for pruritus. J Am Acad Dermatol 2008; 59:234.
2. Neloska L, Damevska K, Kuzmanova A, et al. Dermatological diseases in palliative care patients: a prospective study of 271 patients. J Dtsch Dermatol Ges 2017; 15:621.
3. NICE. Motor neuron disease: assessment and management NG42. 2016
4. Scottish Palliative Care Guidelines. NHS Scotland. 2016
5. Ständer S, Weisshaar E, Mettang T, et al. Clinical classification of itch: a position paper of the International Forum for the Study of Itch. Acta Derm Venereol 2007; 87:291.
6. Tait P. Therapeutic Guidelines: Palliative Care. Version 4. Austtalian Prescriber 2017; 40:110.

Section 4

CLINICAL PROBLEM MANGEMENT

CHAPTER 11

Progressive Neurological Disorders

Introduction

Neurological disorders can be grouped broadly to either as *short term disorders* where patient will have a near normal recovery (e.g. Bell's palsy or Guillain Barre Syndrome) or as *long-term disorders*. Long term disorders could again be divided as *progressive long term disorders* where patients' neurological deficit will gradually get worse with advancement of pathology leading to shortened life expectancy (e.g. motor neuron disease or dementia) and *non-progressive long term disorders* where the neurological deficit does not progress (e.g. stroke).

Progressive neurological disorders are commonly referred for palliation. Examples for such disorders are motor neuron disease, dementia, Parkinson's disease, multi-system atrophy etc.

Dementia

Dementia is a disorder characterized by decline in cognition involving one or more cognitive domains; learning and memory, language, executive function, complex attention, perceptual-motor, social cognition. Dementia is severe enough to interfere with daily function and independence. Most common form of dementia in older adults is Alzheimer disease (AD, 60-80%), while other causes include vascular dementia, dementia with Lewy bodies and frontotemporal dementia. Distinguishing between different aetiologies and identifying dementia patient suitable for palliative care is best done by a neurologist.

Patients with depression often complain of loss of memory ('pseudodementia' or 'dementia of depression'). True dementia patients are often recognized by their families whereas depressed patients often present by themselves.

Memory loss and associated cognitive dysfunction can occur with certain treatable conditions like hypothyroidism, vitamin deficiencies, normal pressure hydrocephalus and subdural haemorrhage etc. These conditions have to be considered in the differentials at every stage of dementia.

Senile dementia is a term that is no longer used, as most cases of dementia with ageing is now known to be due to AD. Senility is a non-modifiable risk factor for the development of AD. 25% of people above 85 years are estimated to have dementia. Multi-infarct dementia, dementia with lewy bodies and frontotemporal dementia are other examples of progressive degenerative dementias. The prognosis of degenerative dementia group may vary from 2 to >15 years, with the end stage lasting as long as 2-3 years.

Progressive dementia need more intense care as the disease advances.

These patients are usually cared for by the spouse or children. Caring for a dementia patient is not easy and the latter are likely to develop anxiety and depression. Carer education is a very important aspect of managing patients with dementia.

The disease trajectory is a gradual and a slow decline. It is important to recognize where in the disease trajectory the patient is in.

Global deterioration scale is a 7-stage model particularly useful for AD.

- **Stage 1** – no memory loss
- **Stage 2** – very mild cognitive decline

- **Stage 3 –** mild cognitive decline (friends and family can recognize memory issues)
- **Stage 4 –** moderate cognitive decline (neurologist can confidently diagnose Alzheimer's disease – poor short term memory, may forget personal details, difficulty with simple arithmetic)
- **Stage 5 –** moderately severe cognitive decline (beginning to be dependent with daily activities, confusion, disorientation)
- **Stage 6 –** severe cognitive decline (difficult to recognize family members, personality changes)
- **Stage 7 –** very severe cognitive decline (communication and physical system declining)

Indicators of terminal stage dementia

Box 1

- Speech limited to single words or phrases
- Almost totally dependent for daily activities
- Eating less and having difficulties with swallowing
- Loss of ability to self-care
- Bowel and bladder issues
- Being unable to walk or stand, problem setting up and controlling head and becoming bedbound
- Frailty
- Recurrent infections needing frequent admissions
- Pressure ulcers

- Interventions for agitation, constipation and pain may improve the quality of life. Decreasing the number of unnecessary investigations and reducing hospital admissions will in turn reduce the health costs.

The last phase of dementia is particularly challenging given the person's inability to verbally express preferences for their care.

It is advisable to have discussions for future care (advanced care planning – ACP). It is done early in the disease, before the patient loses capacity (see below).

It is important to have a simple, safe environment with attentive staff when managing them. Dementia care includes supporting the family and carers too.

Currently available medications

Cholinesterase inhibitors (e.g., rivastigmine) and memantine are the only currently available symptomatic medications for dementia. Cholinesterase inhibitors are considered symptomatic therapies and are not believed to be neuroprotective or to alter the underlying disease course.

Goals of care

Goals of care in mild to moderate dementia is to focus on quality of life, maintenance of function and reduce carer stress.

In severe dementia it is to ensure maximum comfort, avoid aggressive or futile treatments, avoid enteral tube nutrition and allow natural death.

Motor neurone disease

Motor neurone disease (MND) also known as amyotrophic lateral sclerosis (ALS) is an incurable neurodegenerative disorder causing muscle weakness and disability with relentless progression, leading to death within 3-5 years from diagnosis. Onset of disease can be in one or many of following body regions: limbs, bulbar or rarely respiratory regions. With advancing disease involvement of other regions leads to final clinical picture, ALS. Patients progressively lose functions over time, ultimately becoming bed bound.

Patients with MND face many challenges related to physical, psychological, spiritual and socio-economic aspects.

There is no curative treatment available yet. Riluzole (oral tablet, daily ingestion) and edaravone (cycles of daily IV infusion for 2 weeks, followed by 2 weeks of holiday) are two drugs that may show modest survival advantage.

Palliative care has proved to be beneficial in improving quality of life.

Prognosis of MND is mostly related to the respiratory involvement. It is important to measure forced vital capacity of the patient at diagnosis, which would indicate where patient lies in the disease trajectory. Hence monitoring and documentation of vital capacity and charting them in follow up books is useful. This will help predict when the patient will require non-invasive ventilation (NIV) which is supposed to improve quality of life and to help predict end stage.

MND patients with premorbid vital capacity of less than 1 litre should not receive invasive ventilation in the event of respiratory

failure, unless a previous decision has been made for invasive ventilation, a decision needing lengthy discussion where such decision does not counter ethical norms of care. Those with normal premorbid vital capacity where respiratory involvement from ALS is minimal, invasive ventilation for a life-threatening ventilatory failure is not contra-, indicated because successful weaning off the ventilation is likely once the precipitant of the ventilatory failure is reversed.

With advancement of the disease patients may develop progressive dysphagia, which leads to undernutrition and loss of weight. The patient's weight need to be monitored and documented in follow up notes, in order to predict the timing for significant undernutrition, which indicates the timing for percutaneous endoscopic gastrostomy (PEG) insertion. PEG feeding is known to improve the quality of life patient. However, it should not be performed in the terminal stage of the illness. Since respiratory function is the indicator of stage of the disease, the usual rule of thumb is to look at the vital capacity which, if less than 1 litre, PEG is not thought to be advisable.

Both NIV and PEG in those who require them will, in addition to improving quality of life, also proved to provide a modest survival benefit.

Furthermore, support with mobility, communication, swallowing, secretion management are some of the other aspects of care.

Frontotemporal dementia can coexist, predate or post-date MND in some individuals.

Goal of care:

Support for disabilities in order to keep maximum possible function until end stage is a goal in caring for them.

Recognition of end of life

There are no definite markers to diagnose 'end of life' in MND. However, recurring infections, marked decline in functional status, first episode of aspiration pneumonia, significant weight loss and respiratory involvement may indicate that the patient is approaching 'end of life'.

Recognizing 'end of life' allows preparation of patient and family. It also helps in managing the dying phase better with making anticipatory medications including morphine, midazolam, glycopyrrolate bromide injections available at home.

Advanced care planning

Advance care planning (ACP) is widely considered an essential step toward achieving end-of-life care that is consistent with the preferences of dying patients and their families. Most progressive neurological disorders cause loss of capacity as the disease advances.

This is due to gradual loss of cognition leading to difficulties in receiving information and processing them, loss of language and communication. It may be a good decision to discuss with the patient, issues related to pathology that might arise in the future and do some decision making in advance while capacity is intact in the early stage of progressive neurological disorder.

Who does it and what is the timing for ACP?

Since the ACP discussion involves a lot of serious news, you may worsen psychological suffering of patient. Timing for advance care planning may vary depending on patient readiness to discuss them. This needs to be done by an experienced person with skills in palliative care such as good communication skills, empathy etc.

Advance care planning is done by an expert communicator at a suitable time considering patient readiness to discuss them.

ACP comprises living will, advance refusal to certain treatment options or a durable power of attorney for health care. These tools enable patients to convey future treatment preferences while they are still cognitively intact.

Among the usual topics discussed are resuscitation, advance directives, living will, and use of gastrostomy, NIV, or tracheostomy and planning of death.

References

1.Clinical Management, What Palliative care can do for motor neuron disease Patients and families www.ejpc.eu.com

2.Palliative care for all, Integrating Palliative care into disease Management Frameworks, The Irish Hospice Foundation

Reisberg B, Ferris SH, de Leon MJ, Crook T. The Global Deterioration Scale for assessment of primary degenerative dementia. Am J Psychiatry 1982; 139:1136.

CHAPTER 12

Palliative Respiratory Disorders

The World Health Organisation's (WHO) objectives for improving the management of respiratory diseases in developing countries include decreasing the burden of illness, preventing avoidable deaths and increasing the quality of life in patients. Respiratory patients suffer from a multitude of clinical symptoms dominated by breathlessness.

Apart from breathlessness, fatigue, coughing, muscle weakness, sleeplessness, pain, and symptoms of anxiety and depression add to the patient's distress

Despite the proven benefits of improving quality of life, palliative care remains an unmet need for many patients with chronic lung disease.

Lung cancer, the third most common cancer in Sri Lanka, and pulmonary metastases, the second most common site for spread, are important disease entities which have an urgent need for palliative care services in this country.

A study in 2000 showed that patients with advanced chronic obstructive pulmonary disease (COPD) had worse health related quality of life than patients with advanced cancer. The WHO lists COPD as one of the most common conditions for which palliative care is an appropriate, yet underutilized service.

Across the globe advanced care planning is often poorly done in patients with advanced non-malignant lung disease. Clinicians rarely discuss life sustaining treatment preferences with their patients with COPD and other chronic lung diseases despite the fact that patients are able to indicate their preferences.

Moreover, end of life fears s*uch as concerns about dying and fear of breathlessness, are highly prevalent among patients but are barely addressed by professional caregivers.*

Therefore, systematic assessment of symptoms and functional ability should be standardized in our routine clinical practice so that we may recognize patients' problems and changes over time early enough to intervene and create a meaningful difference in their quality of life.

Managing breathlessness

Introduction

The most widely accepted current definition of pathological breathlessness is as "*A subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity. In a patient this experience derives from interactions among multiple physiologic, psychological, social and environmental factors and may induce secondary physiological and behavioural responses"*

Breathlessness is the cardinal symptom of respiratory disease and it is frequently reported as the main symptom in COPD. Therefore, unlike other symptoms, which require palliation, it is a challenging

task for the treating doctor to decide at which point breathlessness needs to be managed as a symptom.

Adverse effects of poorly managed breathlessness (Box 1)

Box 1

Impaired health status,

Impaired activities of daily living,

Increased health service use and

Serious events.

Shorter survival (an mMRC score ⩾2 is a good indicator of decreased survival time in COPD).

What is the mMRC score?

The mMRC scale is a self-rating tool to measure the degree of disability that breathlessness poses on day-to-day activities on a scale from 0 to 4:

0 - no breathlessness except on strenuous exercise

1 - shortness of breath when hurrying on the level or walking up a slight hill

2 - walks slower than people of same age on the level because of breathlessness or has to stop to catch breath when walking at their own pace on the level

3 - stops for breath after walking ~100 m or after few minutes on the level

4 - too breathless to leave the house, or breathless when dressing or undressing

Principles of care of the breathless patient

Identifying contributory causes

In a given patient the symptom of breathlessness may be due to the underlying respiratory illness which may be cancer or non-cancer or treatment related, or secondary to a comorbid condition.

- Possible contributing causes include advanced cancer, impaired lung function, anaemia and bronchospasm (52%).
- Patients with advanced cancers can develop malignant pleural effusions, pericardial effusions, superior vena cava or airway obstructions, phrenic nerve paralysis, and multiple tumour or pulmonary emboli.
- Treatments with surgery, systemic therapies and radiation, alone or in combination, can result in significant shortness of breath

Multidisciplinary team meetings and collaborative services

The concept of a multidisciplinary team for the management of most respiratory diseases is now well established around the world and is being gradually introduced in Sri Lanka as well.

Pulmonary rehabilitation has been initiated in many centers under the supervision of respiratory physicians in Sri Lanka. However, patients with more advanced disease might not be fit enough to attend several weeks of pulmonary rehabilitation but suffer increasingly from intractable breathlessness. This is the gap that breathlessness services intend to fill.

Pulmonary rehabilitation services should be tailored to the needs of patients rather than the anticipated prognosis.

Interaction with other symptoms

Breathlessness frequently coexists with other symptoms. Its management needs a holistic care approach that takes into account the other symptoms that breathlessness interacts with. The co-occurrence with other symptoms can be termed "symptom clustering".

A definition of symptom clusters that is commonly used is that of two or more interrelated symptoms presenting together with a high level of predictability.

Knowledge of symptoms interacting with breathlessness may also facilitate optimal management of the symptom.

Breathlessness and anxiety are often associated and can create a cycle of worsening of both symptoms. Hence each of these symptoms needs to be addressed simultaneously to provide maximum benefit.

Indications for a palliative care consultation

Ideally, clinicians caring for patients with chronic lung disease should be able to manage most of their patients' palliative care issues. *The initiation of a palliative care consultation should be led by patient or family need rather than by the clinical or physiological stage of the underlying disease* because some individuals will cope with advanced disease, and indeed symptoms, more independently than others, it is not possible to generalize indications for any one person or condition.

Several transition points in chronic lung disease and lung cancer have been identified by patients, carers and clinicians, and confirmed by studies. These should serve to prompt a discussion about goals of care and palliative care:

- The start of new or different treatments, e.g. initiation of oxygen therapy;
- Lack of further life-prolonging treatment options;
- Functional decline associated with increased severity of breathlessness and fatigue
- Frequent exacerbations, e.g. >2 per year;
- Frequent hospitalizations >2 every 6 months;

The trajectory of lung cancer is more clearly defined than chronic lung diseases.

Management of Breathlessness

Breathlessness and the individual's reaction to it involve many different physical sensations, affected by cognition, beliefs, motivation, and social and cultural influences.

If we are to help our patients to optimize the management of this symptom we need to manage their reaction to the sensation of breathlessness by behavioural change.

An example for behavioural change which could be adopted is called the "Breathing, Thinking, and Functioning" model.

At the initial assessment, the clinician seeing the patient will assess which "vicious circle" is the strongest driver of breathlessness (in most people, all the spirals operate to some degree) and target their initial treatment strategy towards overcoming that.

Breathing cycle

Patients for whom this cycle predominates have dysfunctional breathing patterns, and breathing retraining and other interventions that target breathing control may be most useful.

Thinking cycle

People for whom this cycle predominates have unhelpful beliefs or previously unpleasant experiences, or sometimes even a single "trigger event" that has coloured their thoughts and feelings about breathlessness. Giving them correct information about what generates, or will help, shortness of breath, will help avoid deconditioning.

Functioning cycle

Breathlessness research is rich in studies that demonstrate that "deconditioned muscles" have a different structure to those that are exercised regularly, leading to the earlier onset of lactic acidosis and leg fatigue on walking. This "breathlessness → rest → deconditioning → more breathless at lower levels of exertion" has been called the "spiral of disability."

When patients have become very inactive, their muscles need to be reconditioned. Helping them to become active again, perhaps with the use of mobility aids, is the priority.

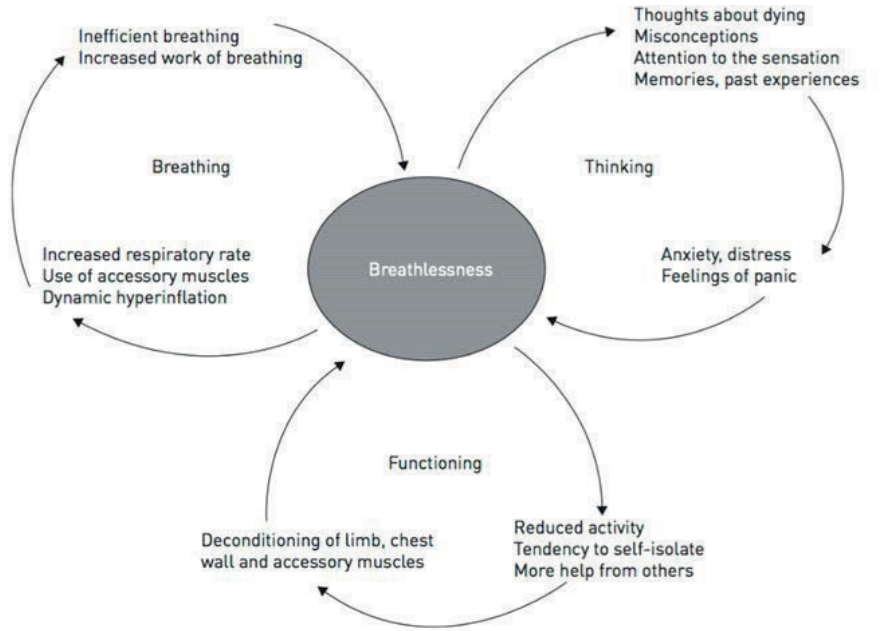


Figure 2. The "Breathing, Thinking, Functioning" diagram used by the Cambridge Breathlessness Intervention Service. ©2014 Cambridge Breathlessness Intervention Service.

Non-pharmacological interventions

Pulmonary Rehabilitation

Physical inactivity is a major consequence of breathlessness. This can precipitate a downward spiral of disease and reduced function. A rehabilitation approach is recommended to counter this spiral. Pulmonary rehabilitation represents the gold standard and should be provided for patients who can tolerate the course.

It can be challenging to encourage patients to start a programme, particularly in the presence of advanced disease and the practical issues such as attending the venue when frail, and fears about the ability to comply with the required level of exercise. The assurance that breathlessness per se is not dangerous, and will often settle with

rest, is a prerequisite to encouraging exercise in people with refractory breathlessness.

Physical activity should be promoted and where relevant supported by the provision of appropriate mobility aids and/or assistive equipment

People who cannot tolerate a full programme of pulmonary rehabilitation because of advanced disease may benefit from chronic breathlessness intervention services that provide many of the same components, but in an individually tailored manner, and in fewer sessions.

Other non-pharmacological intervention components to relieve breathlessness include,

- breathing retraining
- handheld fans
- chest wall vibration (CWV)
- neuromuscular electrical stimulation (NMES) and
- Acupuncture and acupressure.

Breathing retraining- this involves pursed-lip breathing and diaphragmatic breathing. Pursed-lip breathing may reduce respiratory rate and dynamic hyperinflation and may therefore be more effective in certain conditions than others, for example, COPD rather than interstitial fibrosis.

Handheld fans – these have received an increasing amount of attention as a simple and cheap intervention for the relief of refractory breathlessness by directing cool air across the face. The mechanism of action may be the modulation of central perception and reduction of central ventilator drive by airflow stimulation.

Chest wall vibration- while the mechanism is not completely understood, it is likely to involve activation of muscle spindles in the intercostal muscles.

Neuromuscular electrical stimulation of the quadriceps - improves muscle strength and physical performance and can be used in conjunction with pulmonary rehabilitation or as an alternative for patients with severe COPD.

Other non-pharmacological methods include acupuncture and acupressure, relaxation, distractive auditory stimuli and counselling; however, their evidence base remains inadequate

The role of oxygen and airflow for the relief of chronic breathlessness

The role of oxygen in relieving refractory breathlessness in patients with COPD with mild hypoxaemia and normoxaemia remains questionable.

Noninvasive positive pressure ventilation (NPPV)

The sensation of breathlessness strongly correlates with inspiratory load. NPPV reduces inspiratory effort, which is possibly the mechanism by which it relieves breathlessness. The current consensus of professional societies on palliative NPPV for acute respiratory failure recognizes its use in people for whom endotracheal intubation is inappropriate, provided the cause is reversible and NPPV improves patient comfort.

Pharmacological Management

Anxiolytics

The close relationship between breathlessness, anxiety, panic and distress has led to the common use of anxiolytics, such as benzodiazepines, for breathlessness. There is no place for the use of

anxiolytics as first-line treatment of breathlessness unless to treat anxiety/panic if it significantly contributes to breathlessness

Antidepressants

Antidepressants, such as selective serotonin re-uptake inhibitors and tricyclic antidepressants, have been investigated, since serotonin affects the modulation of central respiratory control and sensitivity to carbon dioxide. Furthermore, there is an independent association between depression and breathlessness.

It does seem appropriate that COPD patients with concomitant depression should be actively screened and treated.

Opioid drugs

Opioids have a role to play in safely and predictably reducing chronic breathlessness, with the strongest evidence in people with chronic obstructive disease.

But opioids should only be considered when reversible causes and non-pharmacological measures are optimized.

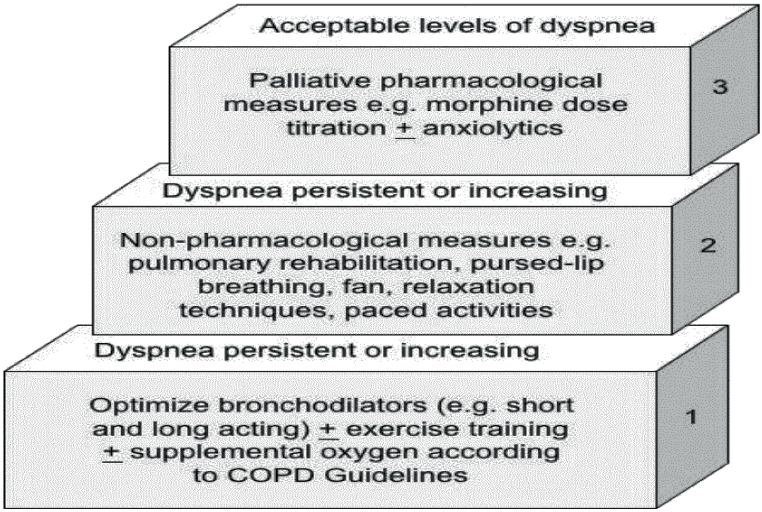
Suggestions on commencing opioids for breathlessness

- Start with small doses of short acting oral morphine i.e.: 2-2.5 mg three to four times daily.
- Gradually titrate and monitor for symptom improvement and side effects.
- Can get converted to long acting oral morphine once satisfactory response is achieved.

For patients already established on opioids for pain, an increment of 25% above baseline is recommended.

Summary of Management

The step-ladder management of breathlessness in COPD amply describes the different modalities which can complement each other in managing this complex symptom.



DYSPNEA MANAGEMENT IN SEVERE COPD

Nonetheless treatment modalities need to be individualized according to the patient and the disease requirement taking in to account the illness trajectory.

The urgent need for training and setting up services such as pulmonary rehabilitation and breathlessness clinics should be repeatedly emphasized as proven and a cost effective management of the increasing number of breathless patients.

This will provide collaborative services to the treating physician and enhance the quality of life of our patients.

References

1. Bausewein C, Currow DC, Johnson MJ, editors. Palliative Care in Respiratory Disease: ERS Monograph. European Respiratory Society; 2016 Sep 1.
2. Dodd JW, Hogg L, Nolan J, Jefford H, Grant A, Lord VM, Falzon C, Garrod R, Lee C, Polkey MI, Jones PW. The COPD assessment test (CAT): response to pulmonary rehabilitation. A multicentre, prospective study. Thorax. 2011 May 1;66(5):425-9.
3. Kocks JW, Tuinenga MG, Uil SM, Van den Berg JW, Ståhl E, Van Der Molen T. Health status measurement in COPD: the minimal clinically important difference of the clinical COPD questionnaire. Respiratory research. 2006 Dec;7(1):1-8.
4. Mahler DA, Wells CK. Evaluation of clinical methods for rating dyspnea. Chest. 1988 Mar 1;93(3):580-6.
5. Spathis, A., Booth, S., Moffat, C. *et al.* The Breathing, Thinking, Functioning clinical model: a proposal to facilitate evidence-based breathlessness management in chronic respiratory disease. *npj Prim Care Resp Med* **27,** 27 (2017)

CHAPTER 13

End-stage Liver Disease

Introduction

Liver disease is increasing in prevalence. Those with chronic liver disease progress through stages of cirrhosis and eventually to "end-stage liver disease" (ESLD) and death.

Initially patients are in a state of compensated liver disease and later progress to a decompensated stage. Each of these stages are characterized by different complications.

	Definition	Mortality per year
Stage 1	Compensated cirrhosis with no esophageal varices	1%
Stage 2	Compensated cirrhosis with varices	3-4%
Stage 3	Decompensated cirrhosis with ascites	20%
Stage 4	Decompensated cirrhosis with GI bleeding	57%
Stage 5	Infections and Renal failure	67%

It is important that we identify these stages as their treatment goals and prognosis vary.

Median survival for compensated cirrhosis is more than 12 years and drops to about 2 years once decompensated Liver transplantation is the only permanent cure for decompensated cirrhosis. Liver transplant surgery itself is a complex surgical

procedure with significant risk of mortality and patients need to be on lifelong immunosuppression after transplant. Therefore, some patients with decompensated cirrhosis do not qualify for liver transplantation due to associated co-morbidities. Due to scarcity of suitable organs for transplantation some patients die while waiting for liver transplantation.

In decompensated cirrhosis the main aim is symptom control and management of complications. It is paramount that we communicate this information with the patient and their carers and manage their expectations accordingly.

However, cirrhosis due to some etiologies will regress with the treatment of underlying etiology and removal of the causative factor. Permanent abstinence from alcohol has been shown to result in regression of liver disease. Disease specific treatment of viral hepatitis, Wilsons disease and autoimmune hepatitis would also improve the long term outcome. New direct acting anti-virals for Hepatitis C virus has been shown to be associated with re-compensation and improved survival in patients with decompensated cirrhosis. Therefore, detailed clinical assessment of the etiology and complications of cirrhosis and thorough diagnostic work up is essential in all patients with cirrhosis.

Patients with ESLD experience numerous complications due to portal hypertension and due to the chronic nature of the disease itself (see box 1).

Box 1

Complications of cirrhosis

Bleeding	Jaundice
Ascites and edema	Hepatic encephalopathy
Fatigue	Pruritus
Muscle cramps	Pain
Anorexia	Psychological symptoms
Pleural effusions	Hydrocele

Despite significant improvements in the treatment of these complications, patients still suffer reduced quality of life and must confront the fact that their disease will often inexorably progress to death. Patients and families struggle with having to simultaneously hope for a cure and face a life-threatening illness.

Ideally, the combination of palliative care with life-sustaining therapy can maximize the patients' quality and quantity of life. If it becomes clear that life-sustaining therapy is no longer an option, these patients are then already in a system to help them with End-of-life care.

Assessment

Child-Turcotte-Pugh (CTP) score remains the most commonly used and simple method in staging chronic liver disease.

Box 02: CTP score

Clinical and Lab Criteria	Points*		
	1	2	3
Encephalopathy	None	Mild to moderate (grade 1 or 2)	Severe (grade 3 or 4)
Ascites	None	Mild to moderate (diuretic responsive)	Severe (diuretic refractory)
Bilirubin (mg/dL)	< 2	2-3	>3
Albumin (g/dL)	> 3.5	2.8-3.5	<2.8
Prothrombin time			
Seconds prolonged	<4	4-6	>6
International normalized ratio	<1.7	1.7-2.3	>2.3
Child-Turcotte-Pugh Class obtained by adding score for each parameter (total points) Class A = 5 to 6 points (least severe liver disease) Class B = 7 to 9 points (moderately severe liver disease) Class C = 10 to 15 points (most severe liver disease)			

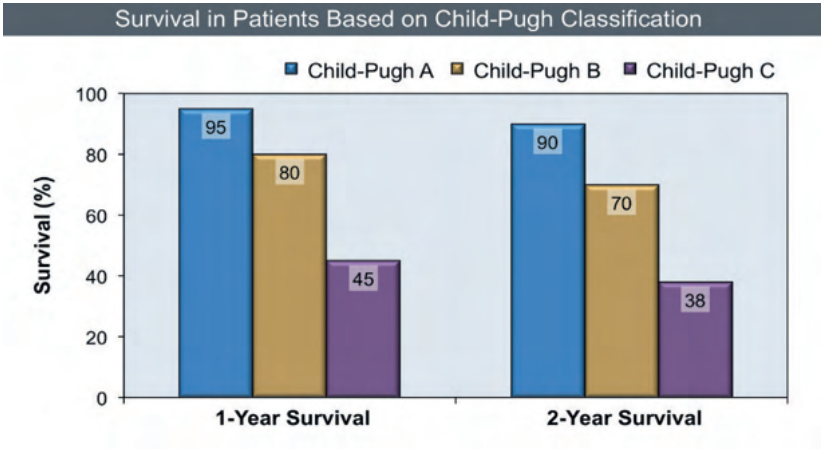
Table 2. WHC and Clinical Description

WHC Including MHE	ISHEN	Description	Suggested Operative Criteria	Comment
Unimpaired		No encephalopathy at all, no history of HE	Tested and proved to be normal	
Minimal	Covert	Psychometric or neuropsychological alterations of tests exploring psychomotor speed/executive functions or neurophysiological alterations without clinical evidence of mental change	Abnormal results of established psychometric or neuropsychological tests without clinical manifestations	No universal criteria for diagnosis Local standards and expertise required
Grade I	Covert	• Trivial lack of awareness • Euphoria or anxiety • Shortened attention span • Impairment of addition or subtraction • Altered sleep rhythm	Despite oriented in time and space (see below), the patient appears to have some cognitive/behavioral decay with respect to his or her standard on clinical examination or to the caregivers	Clinical findings usually not reproducible
Grade II	Overt	• Lethargy or apathy • Disorientation for time • Obvious personality change • Inappropriate behavior • Dyspraxia • Asterixis	Disoriented for time (at least three of the followings are wrong: day of the month, day of the week, month, season, or year) ± the other mentioned symptoms	Clinical findings variable, but reproducible to some extent
Grade III	Overt	• Somnolence to semistupor • Responsive to stimuli • Confused • Gross disorientation • Bizarre behavior	Disoriented also for space (at least three of the following wrongly reported: country, state [or region], city, or place) ± the other mentioned symptoms	Clinical findings reproducible to some extent
Grade IV		Coma	Does not respond even to painful stimuli	Comatose state usually reproducible

All conditions are required to be related to liver insufficiency and/or PSS.

Adopted from Vilstrup H et al. Hepatology August 2014

WHC – West Haven Criteria



Adopted from D'Amico G et al. J Hepatol. 2006; 44:217-3

Model for End-Stage Liver Disease (MELD) scores is the other most widely used tool for prognostication, and comprises the INR, bilirubin and creatinine.

The CTP and MELD scores are reliable measures of mortality risk in ESLD but fails to represent the struggles of many patients.

Those with recurrent gastrointestinal hemorrhage, encephalopathy, ascites, pruritus, sleep cycle disturbance and muscle cramps may never reach a high MELD score which is the criterion for listing for liver transplantation. All patients with cirrhosis should be assessed by a clinician experienced in managing liver diseases to decide on further management.

Symptom management

Intensive symptom management is an integral role for palliative care in many illnesses. Appropriate medication selection and dosing in ESLD is often difficult. A majority of drugs are metabolized in the liver and liver failure may lead to accumulation of medications or toxic metabolites. Decreased hepatic blood flow leads to slower drug metabolism and higher bioavailability. This amounts to a higher risk of adverse effects and often leads to less aggressive symptom management.

Ascites

- Sodium restriction to ≤ 2000 mg/daily
- Oral diuretics: furosemide and spironolactone
- Fluid restriction is not indicated unless serum sodium is <125 mmol/L. However, fluid restriction contributes to worsening quality of life, which is an important consideration in palliative care
- All patients with ascites should have a diagnostic paracentesis each time they admit with decompensation, irrespective of the suspected cause for decompensation. For diagnostic needle paracentesis, correction of the INR and platelet count is not required. Cell count and albumin/protein content of ascetic fluid are important in making management decisions.
- White cell count >500 /mm^3 or neutrophil count of >250 /mm^3 in ascetic fluid indicates spontaneous bacterial peritonitis (SBP) and needs appropriate antibiotics. Response to antibiotics should be assessed by a repeat

diagnostic paracentesis performed after 48 hours; reduction of WBC to <25% of the baseline value indicates adequate response to therapy. Preferred empiric antibiotic for SBP is IV third-generation cephalosporins (e.g., ceftriaxone or cefotaxime). Once the infection is successfully treated lifelong prophylactic antibiotics should be started.

- Refractory ascites: If tense painful ascites is present and does not respond to sodium restriction and diuretics, then paracentesis with albumin replacement (6-8 g per liter removed) for >5 L paracentesis should be initiated. However, when the patient is dehydrated and looks malnourished on clinical assessment, IV albumin infusion can be used even in lower volumes of paracentesis. When IV albumin is not available, IV fresh frozen plasma can be used as an alternative. Paracentesis can be done every 10-14 days for patient comfort.

- Hepatic hydrothorax is the accumulation of transudate (pleural fluid: serum albumin gradient is >1.1g/dl) in the pleural space in the absence of cardiac and pulmonary disease in a patient with decompensated cirrhosis. First-line treatment is diuretics and if the patient has dyspnea therapeutic thoracentesis is indicated. Appearance of hepatic hydrothorax indicates end stage cirrhosis and patient should be evaluated for liver transplant.

- Concurrent use of angiotensin-converting enzyme (ACE) inhibitors, angiotensin receptor blockers (ARB) and nonsteroidal anti-inflammatory drugs (NSAIDs) should be avoided, as they are known to precipitate renal impairment. Beta-blockers should be temporarily withheld, especially in a decompensated liver disease with low blood pressure.

- If more frequent paracentesis is required in the setting of quickly re-accumulating ascites, compliance with low salt diet should be assessed. When acetic fluid re-accumulates despite low salt diet, consideration should be given to using portosystemic shunts.

Hepatic encephalopathy

- Diagnosis of Hepatic encephalopathy

    1. Presence of features suggestive of Hepatic encephalopathy
    2. Presence of severe liver insufficiency
    3. No other obvious cause for brain dysfunction (E.g., eizures, ocal neurological signs)

- Precipitants: dehydration (overdose of diuretics and laxatives), gastrointestinal hemorrhage, infections, renal and electrolyte imbalances, constipation, and medications (opioids and benzodiazepines).

- Management of hepatic encephalopathy – *Four-Pronged approach*

    1. Care for patient with altered level of consciousness: airway protection, intensive monitoring.
    2. Look for alternative causes and treat accordingly.
    3. Identify precipitating cause and correct: 90% of patients get better.
    4. Start empiric treatment.

- Empiric treatment of hepatic encephalopathy

    1 Nonabsorbable disaccharides: lactulose 10-30 ml TDS

2. Antibiotics: metronidazole 200 mg TDS or rifaximin 550 mg BD

- Blood ammonia levels do not need to be routinely checked, because they provide little diagnostic or prognostic value.

- Protein restriction can be harmful, due to increased protein requirements in ESLD patients, and thus is not recommended

If after above treatment for 72 hours no improvement is seen, other causes of impaired consciousness need to investigated for. Eg. Intracerebral Haemarrhage, Ischemic stroke, Encephalitis

Variceal bleeding

If there is evidence of bleeding, patients need to be managed in a hospital setting with pharmacological therapy (blood/fluids, vasopressors and antibiotics) and urgent endoscopy. Prior to performing invasive procedures and starting aggressive medication, patients' expectations and pre-morbid wishes should be taken into consideration. Short term prophylactic antibiotics with 3rd generation cephalosporins improves survival in acute variceal hemorrhage. If 3rd generation cephalosporins are no available quinolones can be used.

Jaundice

Jaundice can be a symptom of decompensation, which might be an acute on chronic decompensation or chronic decompensation, or due to biliary obstruction. It is important to make this distinction, as treatment vary. Jaundice is associated with loss of appetite, fatigue and pruritus. It can be reversed if identified and correctly treated.

There may be a reversible component to the acute decompensation: infections, the disease per se, toxins like alcohol and hepatotoxic medications. These should be looked for and treated. Biliary obstruction could be corrected by an endoscopic intervention.

Two simple tests: liver function test and a USS abdomen will be able to evaluate this at most times.

Pain

No randomized trials or large epidemiologic studies of pain management in ESLD have been conducted, and data is limited to small case series and preclinical data.

Physicians may be reluctant to prescribe opioids in CLCD.

Opioids may precipitate or worsen hepatic encephalopathy. Constipation is a common side effect of opioids and may also exacerbate encephalopathy. Despite these limitations, opioids may be required for management of moderate-to-severe pain particularly at the end of life. When indicated, initiation at low doses and slow up-titration of dosing is generally recommended.

Morphine, oxycodone, and hydromorphone have decreased clearance in patients with ESLD, so should be given in reduced doses and at increased intervals. Both fentanyl and methadone have not shown altered pharmacokinetics in patients with cirrhosis, and could be used, although they have not directly been studied in patients with ESLD. Fentanyl and methadone are safe options in patients with cirrhosis who need pain relief due to a terminal illness.

Pregabalin and gabapentin can also be used for pain relief when appropriate.

- Short-term use (less than 13 days) of acetaminophen at a dose of 4 g/d has not shown to have any adverse effects. For longer term use, it is recommended to reduce the dose to less than 2g/d.

- Non-steroidal anti-inflammatory drugs (NSAIDs) have many adverse effects, including increased risk of renal failure and hepatorenal syndrome due to inhibition of prostaglandins. NSAIDs may also increase risk of mucosal bleeding and interfere with the effect of diuretics, and are therefore best avoided.

Pruritus

The pathogenesis of itching is not fully understood but is felt to be related to accumulation of bile salts, bile acids, and bilirubin in the circulation and tissues along with elevated endogenous opioids. Obstructive jaundice must be excluded as a cause of pruritus while initiating symptomatic treatment.

Non-pharmacological management: skin moisturizers, avoid hot environment and skin irritants

Medications:

- Ursodeoxycholic acid (UDCA) 15 mg/kg.
- Bile acid resins: cholestyramine up to 4 g given four times a day.
- Serotonin and norepinephrine inhibitors: sertraline 75-100 mg daily, mirtazepine 7.5-15 mg at bedtime.

- Tricyclic antidepressants: doxepin 10-25 mg at bedtime, can be increased to 100-150 mg daily.
- Opioid antagonists: naltrexone 25-50 mg daily.
- Sedating antihistamines: in general, antihistamines have shown limited relief of pruritus caused by cholestasis.

Muscle Cramps

Painful muscle cramps that result in sleep deprivation and a decreased quality of life.

The underlying mechanism of muscle cramps in cirrhosis is still not fully elucidated, but possibilities include alterations in three overlapping categories: nerve function, energy metabolism, and electrolytes and plasma volume.

There is no strong evidence to support the use of any one particular intervention over another.

Nerve dysfunction in cirrhosis may be due to structural alterations and oxidative stress leading to increased excitability of motor neurons.

Treatment

- Baclofen starting at a dose of 10 mg/day, with weekly increase up to 30mg/day has been shown to reduce muscle cramps in cirrhosis.
- Vitamin E (400 micrograms twice daily), quinine sulfate (200 mg twice daily),
- Eperisone hydrochloride (a muscle relaxant; 150–300 mg daily) have been shown to be effective in small studies.

- The risk-benefit ratio for using quinine/quinidine in the treatment of cramps in cirrhosis is unfavorable.
- Altered regulation of amino acid and protein metabolism in cirrhosis likely contributes to muscle cramps. Supplementation with taurine (3 g daily) and branched-chain amino acids (isoleucine, leucine, and valine) seems effective based on results of small, controlled studies.
- Shifts in plasma volume may also contribute to cramps. Serum electrolyte concentrations and use of diuretics cause cramps by indirectly influencing plasma volume.
- Intravenous albumin at 25% concentration and zinc (220 mg twice daily) have been effective in small studies.

Depression

Psychiatric comorbidities are thought to be quite common in patients with ESLD. Those with depression experience more physical symptoms, have worse QOL, and are more likely to die while awaiting transplant. This discrepancy is not explained by illness severity alone.

Similar to patients with cancer, diagnosing depression may be challenging due to the frequent overlap of somatic symptoms such as fatigue, lethargy, and insomnia. Liaison with a psychiatrist is essential before starting treatment.

Malnutrition

Resting energy expenditure relative to the lean body mass is increased in patients with cirrhosis. Patients with cirrhosis frequently have either global malnutrition or alterations in specific aspects of nutritional status, such as micronutrient deficiencies, due to multiple mechanisms. Poor dietary intake, poor absorption, and increased losses may contribute.

Malnutrition is implicated in worsening ascites, hepatic encephalopathy, functional ability, and QOL.

Protein restriction is not recommended. It is essential to take at least 1.2 g per kg/day of protein per day. Plant and dairy protein is better than animal protein. Do not restrict protein in hepatic encephalopathy.

Evenly spaced out small frequent meals and a late-night snack: ascites prevents large meals, low glycogen stores cause muscle wasting and nausea. Avoid prolonged periods of fasting.

Take a multi vitamin: need zinc supplementation especially.

Salt restriction is the only restriction in diet that is required. Salt supplements in hyponatremia in cirrhotic patient can aggravate ascites. In ESLD this needs to be balanced against further reducing palatability when the appetite is already compromised.

Waiting for a transplant

Patients with increasingly high MELD scores are undergoing transplantation, which results in prolonged wait times for those who may have profound symptoms despite low or moderately high MELD scores. For other patients' ineligible for transplant, the prospect of relief is poor.

Liver transplantation unfortunately is a scare resource. The patient often has to wait months to years before a suitable match is found. This is while their condition deteriorates and symptoms progress. This time period can be exhaustive to the patient and the family. Transplant listed patients face a dichotomy of parallel paths where they must simultaneously prepare for death and a new life. In fact, there are few medical conditions in which patients face certain death and have the possibility of being essentially cured. Given this paradox, active listing for liver transplant should not preclude palliative care referral.

This is also a time the family would be fighting a battle between giving the best to the patient and managing their own limitations, especially financially. Patient and the family may lose trust in the clinician and seek complementary and alternative medicine CAM). Therefore, it is paramount that the clinician guides their patients through this period and gives realistic goals and information.

A move towards concurrent palliative care would be a major paradigm shift for patients on the transplant waiting list.

Advance care planning

Goals of care and advance care planning seem to be discussed less frequently with ESLD patients compared with cancer patients.

This can be due to cultural reasons, lack of resources and time, poor knowledge and lack of confidence from the clinician's part to handle such situations or merely insensitivity. There is an inherent difficulty in discussing advance directives with patients pursuing curative therapies and setting treatment ceilings or "do not resuscitate" (DNR) orders can be considered controversial for

patients awaiting transplantation. In certain patients with ESLD, escalating treatment, ICU care and resuscitation may be futile and not in the best interest of a seriously ill patient.

It is imperative to discuss goals of care and identify health care proxy agents promptly, as encephalopathy can impact decision making of the patient.

References

1. Cardenas A, Ginès P. Management of complications of cirrhosis in patients awaiting liver transplantation. J Hepatol. 2005;42(1 Suppl):S124–33.
2. Chiara Mazzarelli, Wendy M. Prentice, Michael A. Heneghan et al. Palliative Care in End-Stage Liver Disease: Time to Do Better? Liver Transplantation 24 961–968 2018.
3. Patel AA, Walling AM, May FP, Saab S, Wenger N. Palliative care and healthcare utilization for patients with end-stage liver disease at the end of life. Clin Gastroenterol Hepatol. 2017;15(10):1612–9.
4. Poonja Z, Brisebois A, van Zanten SV, Tandon P, Meeberg G, Karvellas CJ. Patients with cirrhosis and denied liver transplants rarely receive adequate palliative care or appropriate management. Clin Gastroenterol Hepatol. 2014 Apr;12(4):692–8.

CHAPTER 14

End-stage Renal Disease

Introduction

There has been a rising incidence and prevalence of chronic kidney disease in Sri Lanka. This is a heavy burden on the free health services as the cost involved is high and the outcome is poor. The increasing incidence and prevalence in agricultural communities with chronic kidney disease of unknown aetiology (CKDu) and diabetic kidney disease in other areas of the country have contributed to this. Owing to the increase in number of patients as well as the disease-related morbidity and mortality, renal failure has become a major health issue. Advanced renal failure differs from other major organ failures as three modalities of replacement therapy are available. A relatively young adult population is affected in the CKDu category while an older population is affected in the urban communities where diabetes is the main aetiology.

Symptom burden is significant in advanced renal disease and is similar to the symptom burden in advanced cancer. However, there are differences in the type and severity of symptoms as some uraemic symptoms are relieved by dialysis, although the symptom burden of those receiving dialysis remains high.

The relationship between the renal patients and the healthcare team is a stronger one than in many other chronic diseases. The transition from living with renal disease to deteriorating status will be difficult for the patient and the caregivers and should be managed well.

Palliative and supportive care would be beneficial in patients

- Who opt for conservative management of renal failure or deemed high risk for renal replacement therapy.
- Patients who deteriorate while being on dialysis initially
- Patients whose symptoms worsen rapidly despite dialysis therapy

Symptom identification and treatment is a high priority for patients and families, as it improves their quality of life. Some symptoms, including those more common in the renal population, may be poorly recognized by those with little renal experience, resulting in poor symptom management. Unpleasant symptoms experienced by the patients in renal failure should be palliated whether or not active dialysis is being offered. The aim must be to determine the cause of the symptoms prior to treatment.

In conservatively managed Stage 5 chronic kidney disease (CKD 5) See Box 1, symptoms and functional status can often be relatively stable until the 1–2 months preceding death. This is in marked contrast to trajectories for cancer patients or those with chronic obstructive pulmonary disease or cardiac failure.

Box 1

Stage	eGFR ml/min
1	≥60
2	60-89
3	30-59
4	15-29
5	<15

Pain

Pain is extremely common in CKD stage 5 and could be due to renal and nonrenal causes. Musculoskeletal pain, dialysis-associated pain, peripheral neuropathy and peripheral vascular disease are some common non-renal causes.

Some causes of pain are specific to renal disease. Polycystic kidney disease can cause chronic abdominal pain. Secondary hyperparathyroidism often results in bone pain while adynamic bone disease is also a cause for the pain and increasing morbidity. Calciphylaxis (Box 20 a relatively rare cause of severe generalized pain that occurs almost exclusively in patients receiving dialysis. In addition, dialysis patients are subjected to multiple invasive procedures to have a functioning vascular access which often needs adequate analgesia.

Box 2

Calciphylaxis is a rare and serious disorder that presents with skin ischemia and necrosis and is characterized histologically by calcification of arterioles and capillaries in the dermis and subcutaneous adipose tissue

Analgesics and renal failure

Prescribing analgesics must take into account the likely aetiology of pain as well as the patient's renal function and dialysis status. Some analgesics should be avoided, whereas the dosage of others must be adjusted. WHO analgesic ladder can be applied for the management of pain.

- For mild pain, paracetamol can be used safely but dose should be no more than 3g for 24 hours. Nonsteroidal anti-inflammatory drugs (NSAIDs) should generally be avoided in patients with end-stage renal disease (ESRD) because uremia causes platelet dysfunction and increases the risk of gastrointestinal bleeding. NSAIDs should always be avoided in patients receiving peritoneal dialysis, as in this type of dialysis adequate solute clearance and maintenance of volume balance depends on small amounts of residual renal function, which may be adversely affected by NSAID use.
- For moderate to severe pain, tramadol can be used cautiously but requires dose adjustment and an increased dosing interval; the maximal dosage should not exceed 50 to 100 mg twice daily.

Many patients will require opioid analgesics to achieve adequate pain control. Fentanyl which is metabolized in the liver and is not removed by dialysis, and methadone which has faecal excretion and is not removed by dialysis, are considered the safest opioids for use in patients with renal failure.

- Morphine should be used with caution for chronic use in renal failure due to accumulation of neurotoxic metabolites. Preferred opioids include hydromorphone, fentanyl, methadone, or buprenorphine.

- The metabolite of pethidine has half the analgesic activity of pethidine but a longer elimination half-life (8–12 hours); accumulating with regular administration, or in renal failure. It is toxic and has convulsant and hallucinogenic effects.

- Hydromorphone is mostly metabolized in liver, but one active metabolite accumulates in patients with renal failure.

Thus the dosage should be reduced and monitored closely. The active metabolite is removed by dialysis but may accumulate between sessions.

- Oxycodone is mostly metabolized in liver, but a small amount is excreted in urine; use reduce dosage and monitor closely.
- On the other hand, codeine is metabolized to morphine, its active metabolites accumulate in patients with renal failure causing respiratory depression, hypotension, and narcolepsy and should be avoided.

Pain management in chronic kidney disease

1). Establish aetiology where appropriate and treat accordingly

2). Analgesics as per the WHO analgesic ladder and modified to suit the stage of CKD

Dosage alteration in renal failure

Glomerular filtration rate (mL/ min/ 1.73 m2)	Initial opioid dose, as percentage of usual dose		
	Morphine	Methadone	Fentanyl
> 50	100	100	100
10 to 50	50-75	100	75-10
< 10	20	50-75	50

3). Addition of specific therapy to ameliorate pain

Thus the dosage should be reduced and monitored closely. The active metabolite is removed by dialysis but may accumulate between sessions.

- Oxycodone is mostly metabolized in liver, but a small amount is excreted in urine; use reduce dosage and monitor closely.
- On the other hand, codeine is metabolized to morphine, its active metabolites accumulate in patients with renal failure causing respiratory depression, hypotension, and narcolepsy and should be avoided.

Pain management in chronic kidney disease

1). Establish aetiology where appropriate and treat accordingly

2). Analgesics as per the WHO analgesic ladder and modified to suit the stage of CKD

Dosage alteration in renal failure

Glomerular filtration rate (mL/ min/ 1.73 m2)	Initial opioid dose, as percentage of usual dose		
	Morphine	Methadone	Fentanyl
> 50	100	100	100
10 to 50	50-75	100	75-10
< 10	20	50-75	50

3). Addition of specific therapy to ameliorate pain

Neuropathic pain

- CLONAZEPAM - useful adjuvant for neuropathic pain in ESRD 500 microgr PO or SC 12-hourly, maximum dose 1 mg in 24 hours.
- AMITRIPTYLINE – No dose reduction required but sedation may be more prominent in renal impairment. Commence at 10 mg noctė and titrate slowly and carefully.
- GABAPENTIN – Reserved as second line agent. Requires significant dose reduction in renal impairment. 100 mg noctė increasing to 100 mg TDS over a week
- PREGABALIN – Dosage reduction by 50% in CKD stage 3 and 75% in CKD stages 4/5

Muskuloskeletal pain

NSAIDs may cause an acute reduction in glomerular filtration rate (GFR), sodium and water retention, hypertension, and hyperkalemia and potentially contribute to the progression of CKD. NSAIDs also compromise the gastrointestinal mucosa, inhibit platelet function, and are associated with increased risk of cardiovascular morbidity and mortality. So NSAIDs should only be used in very limited occasions to treat pain in CKD patients.

Management of other symptoms

• Anorexia

Ensure adequate dialysis (minimize uremia); evaluate for and treat depression, gastroparesis, and dry mouth. Depression can usually be treated successfully with medications, with or without counseling. The treatment of depression is generally similar to that

recommended in the general patient population. For gastroparaesis initial pharmacologic treatment is Metoclopramide. In patients who fail to respond to metoclopramide, Domperidone can be tried.Cisapride may be used in resistant cases. Dry mouth is helped with maintaining good oral hygiene, avoiding sucrose, carbonated beverages, juices, and water with additives; regularly sipping water and avoiding medications that may worsen dryness (Eg:- Tricyclic Antidepressants, Antihistaminesetc) Stool softeners, dietary measures, and laxatives should be used when needed to relieve constipation. Seek advice from renal dieticians. Give small, regular meals of whatever patients like. Explanation to family regarding patient's decreased appetite will help the family members.

• Restless leg syndrome

Characterized by unpleasant creeping sensation in the extremities and compulsive need to move the legs. It is more common at night and may be relieved by movement. Specific cause unknown. Iron deficiency and dopamine deficiency are implicated.

Treat anaemia and correct iron deficiency.

Clonazepam 500 micrograms at night or doperminergic agonist ropinirole 0.25 mg daily increasing to 4 mg daily, or pramipexole.

Gabapentin has proven benefit in restless leg syndrome in patients without renal impairment and care should be taken because of toxicity with accumulation in CKD.

Massage, warm baths, warm/cool compresses and relaxation techniques may help.

• Nausea and vomiting

Commonly caused by uremia. Should identify the cause and treat accordingly.

Usual antiemetics. Use metoclopramide, but if eGFR<20 use 50% of normal dose.

If ineffective, consider haloperidol SC or i/m, 500 μg to 1 mg 8-hourly.

• Shortness of breath

Aetiology should be identified and treated accordingly.

Acidosis: Adequate dialysis, oral NaHCO3 600-1200 mg tds.

Fluid overload: Adequate dialysis, careful management of fluid balance and dietary advice to reduce salt and water intake. High dose furosemide 80-500 mg per day where residual renal function is present.

• Anaemia

Identify and treat the cause. Correct anaemia with haematinics and erythropoiesis stimulating agents when no other cause is found.

• Muscle cramps

Poor blood circulation, electrolyte imbalances and neuropathy can cause cramps and should be treated accordingly. Both quinine and vitamin E may help in reducing cramps.

• Pruritus/itchy skin

Hyperphosphatemia, uremia and dry skin can contribute to pruritus. Adequate dialysis and use of phosphate binders effectively will help.

Calcium carbonate, lanthanum carbonate, and sevelermar hydrochloride can be used as phosphate binders. Dietary advice from renal dietician to reduce phosphate intake will also help.

Emollients with high water content to hydrate the stratum corneum. If simple emollients fail, evening primrose oil which is rich in essential fatty acids may be used.

Antihistmines: cetirizine, chlorpheniramine and loratadine will help symptomatically.

It may represent a form of sensory neuropathy in a uremic patient, and gabapentin and pregabalin in renally-adjusted doses and carbamezapine may help.

• Delirium and agitation

Haloperidol is safe and commonly used because of its rapid onset of action (reduce dosage by 50 percent); atypical antipsychotics require renal dosing; benzodiazepines are safe but may exacerbate delirium, and are widely used at the end of life.

• Constipation

Reduced diet and fluid intake, Analgesics and other drugs are all potential contributors. Attention to diet and laxatives will help.

References

1. Dahlhamer J, Lucas J, Zelaya C, et al. Prevalence of Chronic Pain and High-Impact Chronic Pain Among Adults - United States, 2016. MMWR Morb Mortal Wkly Rep 2018; 67:1001.
2. Davison SN, Jhangri GS. Impact of pain and symptom burden on the health-related quality of life of hemodialysis patients. J Pain Symptom Manage 2010; 39:477.
3. Fishbein, LJ. Depression in end-stage renal disease patients. Semin Dial 1994; 7:181.
4. Murphy EL, Murtagh FE, Carey I, Sheerin NS. Understanding symptoms in patients with advanced chronic kidney disease managed without dialysis: use of a short patient-completed assessment tool. Nephron Clin Pract 2009; 111:c74.
5. Murtagh FE, Addington-Hall JM, Edmonds PM, et al. Symptoms in advanced renal disease: a cross-sectional survey of symptom prevalence in stage 5 chronic kidney disease managed without dialysis. J Palliat Med 2007; 10:1266.
6. Nigwekar SU, Thadhani R, Brandenburg VM. Calciphylaxis. N Engl J Med 2018; 378:1704.

CHAPTER 15

End-Stage Heart Failure

Introduction

These guidelines have been prepared to support the management of heart failure (HF) patients who are entering the later stages of their condition, emphasizing on symptom management.

Heart failure results from a reduction in the heart's ability to pump blood around the body adequately under optimal cardiac loading conditions, especially during exercise and stress. Patients with HF often have a very poor quality of life and a high mortality rate.

True end-stage HF is reached when,
(1) The patient is chronically and severely symptomatic (NYHA III or IV), See Box 1
(2) No further conventional therapy is available that will provide any realistic prospects of improvement without incurring undue risks to the patient, and
(3) The prognosis is very poor (e.g. life expectancy of <1 year).

Box 1

NYHA classification of Heart failure

Class I: No symptoms of heart failure.
Class II: Symptoms of heart failure with moderate exertion, such as ambulating two blocks or two flights of stairs.
Class III: Symptoms of heart failure with minimal exertion, such as ambulating one block or one flight of stairs, but no symptoms at rest.
Class IV: Symptoms of heart failure at rest.

The prognosis of patients with advanced HF is often difficult to determine for three reasons:
i Diagnostic uncertainty. There is no simple method for measuring organ function accurately in routine clinical practice;
ii The trajectory of deterioration in HF follows a fluctuating course. The many factors causing exacerbation of HF can often improve if the correct therapies are instituted in time;
iii A proportion of HF patients succumb because of sudden cardiac death (SCD). This is generally unpredictable.

The uncertainties about prognosis need to be conveyed and discussed openly with the patient and their family/care givers. Most importantly, the prognosis of HF should not be over-stated, because the natural history of HF, even for those confidently identified as "end-stage" may include some who spontaneously recover and improve, and others who die prematurely through SCD.

Other important considerations for managing later stages of HF include:

- Optimum palliation of the symptoms of HF often depends on close monitoring and adjustments of medication on the clinician's part, and adherence, especially with diuretics, on the patient's part.
- In the event of deterioration of symptoms, a treatable precipitant (E.g. non-compliance with medication, chest infection, anaemia, thyrotoxicosis, recent myocardial infarction, arrhythmia) should be identified and managed promptly.
- Application of a holistic approach: considering physical, psychological, spiritual, cultural and social aspects.
- It is important to elicit particular concerns worrying or frightening the patient and to explore the meaning of a symptom. For example, when pain or breathlessness worsens, do they assume "I am getting worse or I am going to die?"
- Involve other members of the multidisciplinary team, including physiotherapist, occupational therapist, social worker, psychologist, carers, family members and spiritual support as appropriate.
- Try to negotiate the patient's preferred and most appropriate place of care, organizing practical support as necessary
- Establish a plan: whom to contact for advice, symptom management, patient's wishes concerning resuscitation, hospital admissions.

Box 2

Symptoms and issues covered in these guidelines include the following:

Breathlessness	Cough
Pain	Nausea and vomiting
Cachecxia and anorexia	Constipation
Peripheral oedema	Dry mouth
Fatigue	Psychological issues
Spiritual pain	
Terminal heart failure- Last days of life	

Breathlessness

Possible reversible causes of breathlessness other than heart failure should be considered. These include beta-blockers, infection, anaemia and metabolic changes. Fatigue, muscle weakness, anxiety and depression require consideration.

Non-pharmacological management of breathlessness

• Relaxation, breathing-relaxation training, neuroelectrical leg muscle stimulation, or use of a hand-fan and walking-aids

• Psychological support: appreciating impact on lifestyle, anxiety management and education regarding management of panic attack

• Massage, aromatherapy and other relaxation methods

• Spiritual and religious support

• Occupational therapy – lifestyle adjustments to minimize unnecessary exertion and fatigue management

Pharmacological management of breathlessness (These are not in order of priority)

- Humidified oxygen starting at 24%. Do not exceed this concentration if there is co-existent chronic obstructive pulmonary disease (COPD). Nasal specula are often more acceptable than facemasks.

- Glyceryl trinitrate (GTN) Spray 1-2 puffs prn. Contraindicated in severe aortic stenosis.

- Longer acting nitrates. Usually, isosorbide mononitrate (ISMN) MR 30 -120 mg od. GTN patches (10-20 mg) for patients unable to swallow tablets. Important to provide at least 8 hours of nitrate-free period in each 24 hours day. IV nitrates allow closer titration of dose in acute cases.

- Nebulized 0.9% saline +/- bronchodilators, e.g. salbutamol 2 mg or terbutaline 2.5 mg or ipratropium bromide 500 mcg prn

to qds. This may be worth a trial for symptomatic improvement even if there is no measurable change in lung function.

- If co-existing angina, ensure availability of GTN spray, as bronchodilators may precipitate angina.

- Bronchodilators will not be effective if the patient is also taking beta-blockers for heart failure.

- Oral lorazepam 0.5-1 mg prn to max. 4 mg per day – especially if there is an element of anxiety. Diazepam 2 mg orally, can be considered as second-line agents.

- Patients with significant anxiety should initially be considered for non-pharmacological measures with the addition of an anxiolytic antidepressant such as mirtazepine as second line.

- Low-dose oral morphine: morphine should be started at 10 mg per day, given to provide a steady state according to preparation (2.5 mg immediate release regularly four times daily; 5 mg modified release twice daily or 10 mg modified release once daily)

If the response is inadequate, dose increases should not occur for at least one week. Doses can be titrated to a maximum of 30 mg/24 hours of oral morphine.

- If renal impairment or failure is present, use lower starting dose and reduce frequency to twice or thrice daily depending on response.

- In significant renal impairment (Stages 4 and 5 of chronic kidney disease, i.e. GFR <30 mL/min), morphine should be avoided, used with caution, and/or switched to another opioid not having active metabolites with renal excretion.

- Consider use of prophylactic laxative and anti-emetic when commencing strong opioid.

Cough

Productive Cough:

Consider the usual causes of cough such as chest infection or worsening pulmonary oedema.

Non-Productive Cough:

Cough due to ACE inhibitors can begin at any time after commencement, therefore consider a trial of withdrawal for at least 1-2 weeks, even if patient has been taking it for some time. If BP is high, consider replacing with angiotension receptor blockers. If BP is low, simply try withdrawing ACE inhibitors.

If cough continues, consider the following:

- If difficulty in expectoration: nebulized sodium chloride 0.9% PRN. Usual dosage 2.5-5 ml.

- Cough suppressants for dry cough

- Low dose oral morphine (starting dose 2.5 mg every 4 hours as tolerated) PRN. It may also help with breathlessness and pain.

Pain

Pain can be of cardiac (ischaemic) or noncardiac (musculoskeletal), or caused by dyspepsia, gout, peripheral vascular disease, oedematous legs, or due to tense ascites.
The use of pain assessment tools may be helpful. Consideration should be given to the Analgesic Ladder (WHO 2005)

STEP 1:

Non opioids: regular paracetamol

Mild pain of many causes will respond to paracetamol

STEP 2:

Weak opioids +/– non-opioids regular codeine +/- paracetamol. Therapeutic doses of weak opioids are required e.g. codeine 30 mg in combination with 500mg paracetamol.

STEP 3:

Commence normal release morphine sulphate liquid or tablets on a four-hourly regime with access to "as required" doses as well. If opioid naïve, start at 2.5 mg four-hourly, but if already taking full dose of codeine, start at 5 mg four-hourly and 5 mg as and when necessary.

• Titrate the dose up as indicated by the total dose required in the previous 24 hours (regular doses and total prn doses)

Reduce dose frequency and dosage in renal impairment. Paracetamol may still have an additive effect in Step 3 of the analgesic ladder.

In people with severely impaired renal function opioids with a safer metabolic profile, such as methadone, buprenorphine, or fentanyl, are preferred.

- Anti-angina medication if angina occurs

- Spinal cord stimulation might be considered in chronic refractory angina

- Non-steroidal anti-inflammatory agents can worsen heart failure and should be avoided if possible.

- Tricyclics are relatively contraindicated in heart failure. An anticonvulsant such as gabapentin may be safer but as side effects are numerous regular review is necessary.

Nausea and Vomiting

Patients with advanced heart failure may have multiple causes. These include environmental causes such as food or smells and certain drugs.

If nausea is constant and there is renal impairment or renal failure, consider:

- Haloperidol 1.5-3 mg orally subcutaneously at night

If the nausea is related to meals or if there is early satiety and the vomiting of undigested food, this may be related to 'squashed stomach' from hepatomegaly; consider:

- Metoclopramide 10 mg orally three times daily or by continuous subcutaneous infusion 30 mg, over 24 hours
- Domperidone 10 mg orally three times daily If nausea is related to environmental factors such as smells or sight of food, consider

- Haloperidol 1.5-3 mg orally subcutaneously at night, increased to bd as necessary

If the patient is nauseated most of the time, vomiting is considered to have gastric stasis, it may be appropriate to consider administration by alternative routes. A continuous subcutaneous infusion should ensure adequate systemic absorption.

Anti-cholinergics such as cyclizine and hyoscine hydrobromide have the potential for cardiac toxicity and may worsen constipation. They are best avoided.

Cachexia and anorexia

Patients with heart failure may have poor appetite and lose significant amounts of weight.

Poor appetite is exacerbated by breathlessness, fatigue, oedema, drug reactions, renal impairment and depression.

• The combination of reduced nutritional intake and increased requirements place the patient with heart failure at risk of malnutrition

• An unintentional weight loss of 10% in 3-6 months may be due to cardiac cachexia which is not due to malnutrition

• Advice may need to be revised on the basis of reassessment.

Basic advice to improve nutrition

- Assess the patient initially, and check for:
- Required daily dietary intake

- Establishing the patient's likes and dislikes

- Environmental factors which may be contributing to poor nutrition

- Discussion around the patient's hopes and fears

- Identify and treat causative factors

- Renal or hepatic dysfunction
- oedema
- constipation
- Anxiety
- Dry or sore mouth, infections i.e. (oral thrush)
- Nausea
- Ill-fitting dentures and teeth
- Dehydration or over diuresis.
- Possible drug toxicity such as digoxin

Avoid appetite stimulants and/or steroids for treatment of anorexia, as they can increase the risk of cardiac conditions/heart failure and there is no evidence base to support their use.

• In general, give permission for the patient to eat as much or as little of whatever they desire or want.

• Encourage small frequent meals and snacks, and good oral hygiene.

• Many patients may be following a restricted salt diet, based on previously given dietary advice. If they are struggling with the palatability of a no added salt diet, this can be relaxed to improve intake.

- Use of oral nutritional supplemental drinks may be appropriate, so request support from the dietician if required.

When stopping nutritional support: this would only be when the patient is not able to eat or swallow

Act in the patient's best interest and obtain consent

- Be aware that nutritional support is not always appropriate

- Decisions on withholding or withdrawing nutritional support require
  consideration of ethical and legal principles

Peripheral oedema

Longstanding peripheral oedema may result in thin, dry and itchy skin that is prone to cellulitis. Poor peripheral circulation related to co-existing diabetes mellitus or peripheral vascular disease will compound the problem. The oedema may include the arms and genitalia as well as lower limbs.

Pharmacological Management

If oedema is due to heart failure, consider increasing heart failure medication.

Skin care

- Dry skin may be helped by a suitable emollient in the first instance.
- Pruritus may be helped by a mixture of aqueous cream and 0.5% to 1% menthol in aqueous cream
- Elevation of the legs may reduce peripheral oedema and improve comfort
- Compression bandaging is generally not recommended as it can cause skin damage due to inappropriately applied pressure and may increase venous return, thereby stressing an already overloaded organ.
- If there is lymphorrhoea (skin breaks due to leakage of fluid) the limb may benefit from gentle bandaging using retention bandages or turbinate.
- Scrotal supports for scrotal oedema may be helpful.

Dry Mouth

Assess for any underlying cause, an examination of the mouth is required for adequate assessment. Identify if there is co-existing soreness.

A sore dry mouth may be due to a multiplicity of factors including oxygen therapy, medication or underlying oral thrush.

- Consider if any implicated medication could be discontinued?
- Humidify the oxygen (if required)
- Maximize oral hygiene, consider chlorhexidene mouth wash 10 ml twice daily to reduce bacterial count
- Ensure adequate availability of drinks
- Encourage use of chewing gum
- Provide ice cubes to suck
- Prescribe saliva substitutes if available
- Avoid acids in artificial saliva, vitamin C or fruit juices in dentate individuals as they may cause further oral problems.
- Look out for and treat oral candidiasis, usually nystatin 1 lozynge four times a day.

Fatigue

This is a common symptom in end-stage heart failure and requires a full assessment to identify potential reversible causes. Diuretics causing hypokalaemia, anaemia, sleep apnoea and nocturnal hypoventilation and depression may be present either singly or together.

A full history is essential.

Sleep history from patient and family members

Investigate anaemia and if normochromic/normocytic consider the relative risks and benefits of erythropoietin and intravenous iron.

Psychological Issues

It is important to explore underlying psychological issues for patients, families and carers and deal with these if possible by means of a holistic approach involving all members of the multidisciplinary team as appropriate. It may be helpful to explore what the patient thinks is preventing them from sleeping, what makes them anxious; and their fears for the future.

- Non-drug techniques such as relaxation and exercises in breathing control may be useful

- A validated tool for psychological assessment may be helpful in reaching a decision concerning medication

Factors contributing to psychological issues include:

Low mood

- Depression (older individuals with chronic heart failure may be more at risk of developing depression)
- Insomnia
- Anxiety
- Fatigue and lethargy

Depression should be actively sought. The management should be based on

multi-modal interventions (including cognitive behavioral therapy) intervention.

- Antidepressants

Avoid tricyclic antidepressants in view of cardio-toxic side-effects.

Sertraline 50 mg is a suitable first-line agent unless anxiety is also apparent

- Citalopram 10-20 mg daily would be appropriate if anxiety and depression co-existed

- Mirtazepine 15-30 mg nocte is another alternative if nausea or poor appetite are associated problems

Night sedation:
Lorazepam 0.5-1 mg

- First-line Lorazepam 0.5-1 mg sub-lingual especially for panic attacks

- Diazepam 2 mg orally three times daily

- Buspirone 5 mg per oral

Terminal heart failure – the last few days of life

A high proportion of patients with confirmed heart failure, up to 40-50% in some studies, will experience sudden cardiac death, others will deteriorate more slowly. For those patients seen to be approaching the end-of-life the following points and communication issues should be considered
In heart failure patients may achieve improvement with medication and there may have been a reversible precipitant.

- As a patient becomes weaker and has difficulty swallowing there is a need to discontinue non-essential medications and continue those which will provide symptomatic benefit.

- Essential medications as opioid analgesics, anti-emetics and anxiolytics, can be converted to continuous subcutaneous infusions given over 24 hours via a syringe driver with "as required" subcutaneous doses available if needed.

- Inappropriate invasive procedures such as venepuncture and regular measurements of blood pressure and pulse should be discontinued.

- There is a need to consider the cardio-respiratory resuscitation status of the individual and when appropriate discuss this with the patient and the family.

- If the patient has an implantable cardioverter defibrillator (ICD), it is important to consider, and where appropriate discuss with the patient and family, when would be an appropriate time to switch this off.

- Psychological support of patient and family.

- Spiritual care according to patient's cultural and religious beliefs is important.

References

1. Palliative Care for Patients With Heart Failure; Feb 11, 2016; Expert Analysis, Americal College of Cardilogy.
2. Palliative care for people living with heart failure: European Association for Palliative Care Task Force expert position statement, European Society of Cardiology: *Cardiovascular Research (2020)* 116, 12–27
3. Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology; *European Journal of Heart Failure (2009)* 11, 433–443
4. Palliative care in patients with heart failure, *BMJ* 2016, 353:i1010
5. Palliative Care in the treatment of End Stage Heart Failure, *Circulation,* 2009, Volume 120, Issue 25
6. Symptom Control and Care of the Dying Patient: Palliative Care Guidelines – 5th Edition„ Kent palliative care team,
7. Symptom control guidelines, End stage Heart Failure; Cheshire and Merseyside Clinical networks
8. Symptom Management Guidelines for patients in the later stages of heart failure and criteria for referral to specialist palliative care ; West Yorkshire Cardiac Network

CHAPTER 16

Endocrine and Metabolic Abnormalities

The principle of providing comfort and improving quality of life rather than looking into finer biochemical abnormalities and long-term risks is the key to managing endocrine and metabolic disorders in palliative care.

Diabetes Mellitus

Managing diabetes mellitus in palliative care focuses mostly on avoidance of hypoglycaemia, symptomatic hyperglycaemia, dehydration and metabolic emergencies. Focus on prevention of long-term complications would become less clinically relevant. The management decisions on diabetes in palliative care are more complex rather than just a direct choice between continuing medicines versus withdrawing them.

Box 1: Key aspects to consider in making a management plan[1]

- Stage of the disease and estimated life expectancy (stable patient, patient with organ failure, dying patient)
- Nature of diabetes and duration (recent onset type 2 controlled with monotherapy, Type 2 requiring very high insulin doses, difficult to manage type 1, glucocorticoid induced)
- Concerns of the individual and the family/ care giver
- Patient's dietary intake which varies due to the underlying illness
- Setting of the care (hospital, hospice, home)

Box 2: Main components in management

- Revising glycaemic targets to be less stringent
- Modifying medications to match the revised target and patient's clinical status including dietary intake and weight loss
- Selecting a medication regime which is convenient and causing minimal adverse effects to the patient
- Avoiding hypoglycaemia, persistent symptomatic hyperglycaemia and hyperglycaemic emergencies (Diabetes ketoacidosis and hyperosmolar hyperglycaemic state)
- Avoiding restrictive dietary plans
- Preventing pressure ulcers and foot complications in bed bound frail individuals

Monitoring and glycaemic target

Monitoring of these patients should target the minimum required investigations to reduce the distress and inconvenience to the patient and care givers. Plasma blood glucose or finger-stick glucose can be measured infrequently to maintain blood glucose levels in the expected range. HbA1C is usually not indicated[3]. When venepuncture or finger-stick is not welcome by the patient or difficult to perform in the setting, urine sugar tests to make sure that blood glucose levels are not very high is also acceptable.

In a stable patient, target would be to maintain blood glucose below renal threshold while avoiding hypoglycaemia.

In patients with organ failure try to make patient free of hypoglycaemia and persistent symptomatic hyperglycaemia.

In general, consensus is to aim blood following glucose values at a range in most of the patients[1]

- Higher than 110 mg/dL and
- Lower than 270 mg/dL

Pharmacological treatment

Pill burden should be minimized and a convenient regime for the patient and care givers should be arranged. Drugs used for long term cardiovascular benefit are best withdrawn.

Table 1: Guide for the use of hypoglycemic agents[1, 3]

Agent	Recommendation
Metformin	Dose reduction or withdrawal in patients with gastrointestinal disturbances, loss of appetite and loss of weight. Also avoid in severe organ impairment or critical illness due to concern on lactic acidosis.
Sulphonylureas	Risk of hypoglycaemia especially with lower intake and renal dysfunction. Use lower doses and short acting agents with lower risk of hypoglycaemia (gliclazide, glimepiride). Reduce dose in renal failure.
DPP-4 inhibitors (e.g., sitagliptin, linagliptin)	Avoid in pancreatic disease. Adjust dose and withdraw when needed in renal disease for sitagliptin. Linagliptin does not need dose adjustment.
Thiazolidinediones (e.g., pioglitazone)	Causes fluid retention and heart failure. Avoid in patients with oedema or heart failure.

SGLT-2 inhibitors (e.g., empagliflozin, canagliflozin, dapaglifozin)	Avoid in severe renal impairment (eGFR<30). Stop if concerns of dehydration, foot ulceration or risk of genital infections arise. Risk of ketoacidosis would be higher in individuals with starvation or any acute illness.
GLP-1 analogues (e.g., liraglutide, exenatide)	Dose reduction or withdrawal in patients with gastrointestinal disturbances, loss of appetite and loss of weight. Avoid in pancreatic disease.
Insulin	Dose adjustment with reduced oral intake and organ impairment to avoid hypoglycaemia. Basal only or premixed twice daily regimes preferred over basal-bolus regime for convenience. Even in type 1 diabetes basal only regime may be adequate to prevent diabetes ketoacidosis in terminal stages with reduced oral intake.

If insulin is essential, stopping all oral medicines can be considered to make the regime less complex. Insulin administration needs to be revised since patient may find difficult to self-inject with clinical deterioration.

In a dying patient all diabetic medications may be stopped except some basal insulin in type 1 diabetes to prevent distress due to metabolic emergencies.

In patients receiving glucocorticoids further adjustment may be needed to avoid severe hyperglycaemia. In patients on daily glucocorticoids given in the morning additional morning

sulphonylurea or morning isophane insulin would cover the glucocorticoid effect[1].

Diet and nutrition

Food restriction is discouraged. Any food item of their preference should be allowed. Considering the small quantities these individuals consume, high calorie meals including sugary food can be allowed despite their adverse impact on glycaemic control.

Patients on enteral nutrition can be given food to match the energy requirement using available food. Nutrition consultation would be useful. Medication regime including timing can be adjusted to suit the feeding times.

Prevention of hypoglycaemia

Hypoglycaemia in an individual with diabetes is defined as a blood glucose value <70 mg/dl.

Box 3: Measures to prevent hypoglycaemia

- Pay attention to anorexia and weight loss
- Adjust doses of insulin and other oral hypoglycaemic agents
- Adjust treatment according to deterioration of renal and liver functions
- Avoid complex regimens

Features of hypoglycaemia in these individuals might be different from common sympatho-adrenal and neuroglycopaenic symptoms. Certain symptoms could be erroneously attributed to underlying terminal illness as well. Therefore, caregivers and clinicians should

consider hypoglycaemia as a cause for deterioration in these patients which is reversible and would affect quality of life.

Withdrawing treatment

Complete withdrawal of diabetes medications would be considered in the following situations[1],

- Dying patient (Type 1 diabetes would be an exception)
- Frequent hypoglycaemia with small doses of treatment
- When patient is withdrawn from therapeutic feeding and hydration
- Very low-calorie intake
- Where diabetes was controlled with minimal doses of oral hypoglycaemic agents before

Withdrawal of diabetic medications does not mean complete withdrawal of care, rather a change in treatment goals.

Hypoglycaemia in non-diabetic individuals

Hypoglycaemia without diabetes is considered as a random plasma glucose <63 mg/dL.

Box 4: Cause of hypoglycaemia in non-diabetic individuals during terminal illnesses[2]

- Major organ failure: renal failure, liver failure
- Critical illness: sepsis
- Inanition due to prolonged underfeeding or withdrawal of therapeutic feeding
- Hypoadrenalism
- Paraneoplastic syndrome
- Accidental or surreptitious insulin/sulphonylurea administration

Suspicion and recognition of hypoglycaemia would be difficult due to reduced communication, reduced adrenergic symptoms and attribution of symptoms to underlying illness or delirium. Once diagnosed correction is recommended except in patients who are dying, and medications have been withdrawn.

Box 5: Management of hypoglycaemia

- Oral/enteral intake of glucose containing drink/dextrose is recommended if there is no alteration in consciousness
- Intravenous 25% dextrose 50ml bolus is recommended in patients who are unable to take orally
- In the absence of intravenous access, a temporary benefit might be there with buccal application of some glucose
- Subcutaneous or intramuscular glucagon 0.5 to 1 mg is also recommended if available in the setting
- Random blood glucose is measured in 15 minutes and above measures repeated if persistent hypoglycaemia observed
- Rapid correction should be followed by a complex carbohydrate meal to prevent recurrence of hypoglycaemia

Thyroid disease

In treating thyroid disease in palliative care, prevention of symptoms of thyroid disease is more important rather than achieving strict biochemical euthyroid state. Following are the key aspects to be considered.

- Interpretation of thyroid function tests

Non thyroidal illness (sick euthyroidism syndrome), effect of medicines like glucocorticoids and heparin can affect the thyroid function tests.

- Masking and mimicking of clinical features

Symptoms and signs of thyroid disease can be mimicked or masked by underlying illness. Examples include constipation and lethargy of hypothyroidism, loss of weight and tachycardia in thyrotoxicosis.

- Severity and aetiology of thyroid disease

Overt hypothyroidism due to causes such as total thyroidectomy and Hashimoto thyroiditis warrant treatment for symptomatic benefit. Similarly patients with symptomatic thyrotoxicosis should be treated.[5]

Patients with subclinical hypothyroidism do not usually need levothyroxine treatment. In subclinical thyrotoxicosis we recommend making an individualized decision based no degree of TSH suppression, life expectancy and risk and consequences of arrhythmias.

- Estimated life expectancy

In a patient who is close to death, withdrawal of treatment of thyroid disease may be appropriate.

- Available treatment strategies for thyroid disease

In thyrotoxicosis anti-thyroid drugs or radioactive iodine would be preferred over thyroidectomy.

- Monitoring

Less frequent biochemical monitoring may be done unless clinically indicated. In hypothyroidism achieving a TSH of <10 mIU/L would be adequate most of the time to alleviate the symptoms of hypothyroidism[4].

- Issues related to drug administration

In patients who are on enteral feeding and multiple interfering medications administration of these drugs would be difficult. Bioavailability of oral tablets dissolved and administered with meals or other oral agents is unpredictable. Therefore possibility of under

treatment should be kept in mind when changing to enteral nutrition.

Considering all above factors together with patient preferences, an individualized decision should be made on managing thyroid disease in palliative care.

Dyslipidaemia

In almost all patients receiving palliative care it is rational to stop lipid lowering therapy[6]. Minimising pill burden takes priority considering the need to continue these medications for a long time to obtain cardiovascular benefit. Exceptions would be,

- Recent cardiovascular event with high risk of recurrent event in the near future
- Severe hypertriglyceridaemia with risk of acute pancreatitis

In these patients, overall prognosis and benefit of additional drugs should be assessed critically to decide on continuing lipid lowering therapy.

Disorders of calcium homeostasis

Hypocalcaemia

Since spurious hypocacaemia due to low albumin levels is common, confirm with ionized or corrected calcium measurements. Once confirmed the following possibilities have to be considered.

- hypoparathyroidism
- chronic kidney disease
- vitamin D deficiency

- blood transfusion
- hypomagnesaemia
- medications: bisphosphonates, denosumab, chemotherapy (cisplatin)
- osteoblastic metastasis
- tumour lysis syndrome
- recent major surgery
- recent acute illnesses including sepsis

If the aetiology is known, management can be continued to avoid symptoms of hypocalcaemia. Less frequent biochemical monitoring guided by clinical features like parasthaesia, perioral numbness, Chvostek sign and Trousseau sign would be helpful.

In newly diagnosed patients, decision to further evaluate should be based on the overall clinical state of the patient and response of hypocalcaemia to initial treatment. Calcium replacement to keep the patient asymptomatic and avoidance of severe manifestations like seizures and arrhythmias would be a priority.

Vitamin D deficiency is widely prevalent in these individuals. Some studies have shown association with increased pain perception, fatigue and poor quality of life[7, 8]. Treatment with vitamin D might be beneficial though this hypothesis awaits evidence from high quality studies. Especially in the setting of hypocalcaemia testing for vitamin D levels would be appropriate.

If the patient is not responding and continues to be **symptomatic** further testing including parathyroid hormone and magnesium level would be useful.

Hypercalcaemia

Major causes for hypercalcaemia differ depending on the underlying illness.

Table 2: Common causes of hypercalcaemia in cancer and non-cancer settings

Cancer	Non-cancer
• Common in breast cancer, squamous cell lung cancer, renal cancer and myeloma Due to; • Secretion of ectopic parathyroid hormone or PTH-related peptide (PTHrP) from tumour **(>80% cases)** • Increased production of 1,25-dihydroxivitamin D and cyotkines (e.g., IL-1, IL-6, TNF v, TGF) e.g., lymphoma	• Excess use of calcium and vitamin D supplements • tertiary hyperparathyroidism in chronic kidney disease • lithium and thiazide diuretics • Primary hyperparathyroidism

Serum corrected calcium = serum calcium + [(40 - serum albumin) x 0.02]

Normal calcium = 2.1-2.6 mmol/l

Normal albumin levels = 34-52 g/l

Box 6: Management of severe hypercalcaemia

- Hydrate with 0.9% NaCl 2-4 L per 24 hours unless there is a contraindication for aggressive fluid replacement
  (Initial rate of 200 to 300 mL/hour that is then adjusted to maintain the urine output at 100 to 150 mL/hour)

- Intravenous zolendronic acid 4 mg in 100 ml of 0.9% NaCl over 15 minutes (Need dose reduction if eGFR is <60 ml/min/1.73m^2 and avoid if eGFR is <30 ml/min/1.73m^2)

- For patients with significant renal impairment that does not resolve with hydration, give pamidronate at a dose of 60 mg in 500 ml 0f 0.9% NaCl infusion over 2 hours

- Denosumab can be given in renal failure instead of zolendronic acid/pamidronate

- Calcitonin 4-8 IU/kg subcutaneous injections 12 hourly can be given up to 24-48 hours

- The hypercalcaemia will almost certainly recur if there is no treatment for the underlying malignancy.

Additional measures would be considered based on circumstance,

- Intravenous hydrocortisone 100mg 6 hourly followed by prednisolone 40mg daily up to one week is recommended in lymphoma and some other malignancy related hypercalcemia
- Haemodialysis is beneficial in very severe hypercalcaemia with severe neurological manifestations or renal failure
- Calcimimetic agents (cinacalcet) is beneficial in patients with primary hyperparathyroidism not intended for surgery due to a terminal illness

Osteoporosis

Discontinuation of medications for osteoporosis is usually accepted when palliative care plan is agreed upon[6].

In selected patients a decision to continue osteoporosis medications would be made considering following aspects,

- patient's perception on pill-burden and preventive medications
- patient's mobility (a bed bound patient would not benefit)
- ability to tolerate and follow instructions for administration of commonly available osteoporotic medications (e.g., alendronate)
- estimated life expectancy

Following would be useful for fracture prevention as well as overall improved quality of life.

- Measures to prevent falls
- Adequate nutrition intake including calcium and vitamin D
- Keeping the patient physically active as long as possible

Pain management in patients who have had fractures is important and bisphosphonates and calcitonin are beneficial for this indication.

Stable patients receiving palliative treatment for cancer might be treated with bone protection agents since there is accelerated bone loss and risk of early fractures. These include patients receiving aromatase inhibitors (e.g., anastrozole) for breast cancer and androgen deprivation therapy for metastatic prostate cancer[9, 10].

Use of osteoporosis treatment in palliative care of patients with skeletal metastases is beyond the scope of this chapter.

Adrenal insufficiency

New onset adrenal insufficiency can occur in palliative setting due to several reasons.

Table 3: Causes of primary and secondary adrenal insufficiency in palliative setting

Primary adrenal insufficiency	Secondary adrenal insufficiency

• Bilateral adrenal metastasis
• Disseminated infections affecting adrenals: e.g., tuberculosis, HIV infection
• Haemorrhagic adrenal infarction
• Medications: e.g., rifampicin, mitotane, etomidate, ketoconazole, fluconazole
	• Glucocorticoid withdrawal
	• Medications: e.g., opioids, megestrol acetate, medroxyprogesterone acetate
	• Pituitary/hypothalamic lesions
	  ○ Radiation
	  ○ Metastasis
	  ○ Infiltrative disease

Adrenal insufficiency should be suspected in above settings with suggestive features including unexplained hypotension, hypoglycaemia, hyponatraemia, hyperkalaemia and non-specific symptoms such as anorexia, nausea, vomiting, abdominal pain and

weakness. Diagnostic uncertainty can arise due to overlap with symptoms of underlying primary disease.

Morning cortisol value below 100 nmol/L usually rules in adrenal insufficiency. A value above 415 nmol/L is highly unlikely in adrenal insufficiency unless patient is in severe stress like surgery or sepsis[11, 12]. Factors affecting cortisol binding globulin should be considered before interpretation. The standard of dynamic tests like short synacthen test would not be recommended unless there is clinical doubt and reasonable life expectancy. Therefore, in patients with values in between a clinical decision has to be made whether to treat empirically or to test with a dynamic test. Further evaluation to establish level of defect would be less important.

Until the end-of-life corticosteroid replacement for adrenal insufficiency is recommended to prevent adrenal crisis. In primary adrenal insufficiency fludrocortisone should also be continued. With stress of inter-current illnesses dose has to be increased and in patients who cannot tolerate oral medications parenteral administration can be continued unless a decision to withdraw all medications has been made in a dying patient.

Disorders of sodium homeostasis

Hyponatraemia

Hyponatraemia is common in palliative care setting and causes vary depending on underlying illness. Common causes are,

- Electrolyte rich fluid loss due to vomiting, diarrhoea
- Inadequate intake
- Syndrome of inappropriate anti-diuretic hormone (SIADH)

- Hypervolaemic hyponatraemia: heart failure, cirrhosis, renal failure
- Drug induced: diuretics, chemotherapy
- Adrenal insufficiency and hypothyroidism

Be aware about pseudo hyponatraemia (isotonic hyponatraemia) due to severe hyperlipidaemia, obstructive jaundice and paraproteinaemia. Hypertonic hyponatraemia due to hyperglycaemia and mannitol should not be overlooked.

Evaluation and management depend on underlying illness, co-morbidities, medications and volume status of the patient. Mild to moderate chronic hyponatraemia usually is asymptomatic and can be managed conservatively in a palliative care setting.

Acute severe hyponatraemia with risk of neurological effects is recommended to be managed with 3% NaCl according to standard guidelines.

Hypernatraemia

Hypernatraemia could be due to following causes in a patient receiving palliative care,

- Dehydration
    - Excessive water loss from skin/gastrointestinal tract
    - Inadequate fluid replacement
- Diabetes insipidus (DI): cranial DI due to brain metastasis and infiltrative conditions, nephrogenic DI due to hypercalcaemia, hypokalaemia, medications
- Sodium overload: infusion of sodium containing of fluids and medications

Correction of dehydration, addressing symptoms like neurological manifestations and thirst are key to managing these patients rather than detailed biochemical evaluation.

Hypogonadism

Male hypogonadism is seen in many chronic serious illnesses including,

- Advanced cancer
- HIV infection
- Chronic kidney disease
- Cirrhosis
- Heart failure
- Patients receiving opioid analgesics

In these conditions, hypogonadism is shown to contribute to weight loss, symptom burden and impaired quality of life.

In men with HIV and cachexia with no other explained cause, testing for hypogonadism followed by testosterone replacement if there is hypogonadism is recommended[13]. In other conditions there are no recommendations, but an individualized decision should be made[14].

In young females with symptomatic secondary amenorrhoea hormone replacement therapy may be considered for symptomatic therapy, not for long term benefits.

References

1. Diabetes, U., *End of life diabetes care: Clinical Care Recommendations, 3rd.* 2018.
2. Kok, V.C. and P.-H. Lee, *Management of hypoglycemia in nondiabetic palliative care patients: a prognosis-based approach.* Palliative Care: researCh and treatment, 2017. **10**: p. PCRT. S38956.
3. Angelo, M., C. Ruchalski, and B.J. Sproge, *An approach to diabetes mellitus in hospice and palliative medicine.* Journal of palliative medicine, 2011. **14**(1): p. 83-87.
4. Rao, P.D. and K. Prasanna Kumar, *Palliative Care and Endocrine Diseases.* Textbook of Palliative Care, 2018: p. 1-7.
5. Joven, M.H., *Should the treatment of hypothyroidism be withdrawn in hospice care?* Journal of pain and symptom management, 2016. **52**(3): p. e3-e4.
6. Lindsay, J., et al., *The development and evaluation of an oncological palliative care deprescribing guideline: the 'OncPal deprescribing guideline'.* Supportive Care in Cancer, 2015. **23**(1): p. 71-78.
7. Martínez-Alonso, M., et al., *Vitamin D deficiency and its association with fatigue and quality of life in advanced cancer patients under palliative care: a cross-sectional study.* Palliative medicine, 2016. **30**(1): p. 89-96.
8. Whitehurst, J.L. and C.M. Reid, *Vitamin D deficiency as a cause of chronic pain in the palliative medicine clinic: two case reports.* Palliative medicine, 2014. **28**(1): p. 87-89.
9. Pfeilschifter, J. and I.J. Diel, *Osteoporosis due to cancer treatment: pathogenesis and management.* Journal of Clinical Oncology, 2000. **18**(7): p. 1570-1593.
10. Gralow, J.R., et al., *NCCN task force report: bone health in cancer care.* Journal of the National Comprehensive Cancer Network, 2009. **7**(Suppl_3): p. S-1-S-32.
11. Schmidt, I.L., et al., *Diagnosis of adrenal insufficiency: evaluation of the corticotropin-releasing hormone test and basal serum cortisol in comparison to the insulin tolerance test in patients with hypothalamic-pituitary-adrenal disease.* The Journal of Clinical Endocrinology & Metabolism, 2003. **88**(9): p. 4193-4198.
12. Erturk, E., C.A. Jaffe, and A.L. Barkan, *Evaluation of the integrity of the hypothalamic-pituitary-adrenal axis by insulin hypoglycemia test.* The Journal of Clinical Endocrinology & Metabolism, 1998. **83**(7): p. 2350-2354.
13. Bhasin, S., et al., *Testosterone therapy in men with hypogonadism: an Endocrine Society clinical practice guideline.* The Journal of Clinical Endocrinology & Metabolism, 2018. **103**(5): p. 1715-1744.
14. Dev, R., E. Bruera, and E. Del Fabbro, *When and when not to use testosterone for palliation in cancer care.* Current oncology reports, 2014. **16**(4): p. 378.

CHAPTER 17

Haematological Disorders

Introduction

Certain haematological malignancies ultimately require palliative care. Haematological manifestations such as anaemia, neutropenia and thrombocytopenia are frequently encountered in patients in palliative care due to the underlying disease, its complications and or therapy. Aim of management is to improve quality of life. The extent to which an intervention is carried out should be assessed against benefits as they may not impact prognosis, and over-enthusiastic intervention may have detrimental effects.

Management of haematological disorders will be discussed under the following headings in this chapter.

A. Common haematological problems encountered in palliative care
    - Anaemia
    - Neutropenia
    - Bleeding
    - Thrombosis
B. Palliative care in haematological malignancies

A. Common haematological problems encountered in palliative care

1. Anaemia

Introduction

The World Health Organization (WHO) defines anaemia as a haemoglobin (Hb) level of <120 g/l in women and <130 g/l in men.

Anaemia is common in patients with advanced malignant and non-malignant diseases. Anaemia is present in 77% of men and 68% of women receiving palliative care. Determining the cause of anaemia in the palliative care setting can be challenging, since the aetiology is often multifactorial. Disease-related causes include bone marrow infiltration, blood loss, dietary insufficiency due to cancer cachexia, haemolysis, multi-organ failure, and anaemia of chronic disease. Malignancy-related treatment can also result in anaemia due to myelosuppression such as chemotherapy and treatment-associated myelodysplastic syndrome. Concomitant factors such as folate deficiency from malnutrition, anti-metabolite therapy gastrointestinal resection related malabsorption, blind loop syndromes and frequent phlebotomy may also contribute. It is important to understand the cause(s) of anaemia, if possible although investigations to determine the cause may be inappropriate in palliative settings.

Symptoms and signs of Anaemia

- Fatigue.
- Dyspnoea.
- Decreased exercise capacity.
- Diminished overall well-being and decreased appetite.
- Patients often remain symptom-free when the onset of anaemia is gradual.

Causes of anaemia

- Anaemia of chronic disease (ACD).

The diagnosis of ACD is often based on the exclusion of other forms of anaemia, but should always be considered in the palliative

care setting. It is present in almost 50% of men and over 70% of women.

- Acute and chronic blood loss

In patients in palliative care, acute and chronic blood loss is a common phenomenon, especially gastrointestinal, head and neck, respiratory tract, and genito-urinary tract malignancies. Some malignancies can bleed into the tumour itself. This chronic blood loss causes an iron deficient state and leads to anaemia. In addition, repeated phlebotomy for diagnostics may also result in a significant blood loss.

- Nutritional deficiencies

Cancer cachexia is seen in about half of all cancer patients, characterized by anorexia and loss of adipose tissue and skeletal muscle mass, leading to progressive nutritional deficiency. The incidence of vitamin B12 deficiency was similar to that of the general elderly population, at 7%. However, a low serum folic acid level which was significant, and was seen in 22%. It was also noted that, patients with gastrointestinal malignancies and intestinal resections can develop nutritional deficiencies secondary to malabsorption.

- Bone marrow infiltration

This is common in patients with haematological malignancies such as myeloma, lymphoproliferative disorders, leukaemia, and myelodysplastic syndrome etc. Some solid malignancies such as prostate, breast and lung can have marrow infiltration causing anaemia.

How to manage anaemia

- Aim is to improve quality of life and improve symptoms.
- Treatment options available are:
  i. Erythropoiesis stimulating agents (ESA).
  ii. Iron, B12, folic acid, vitamin C and other micronutrients.
  iii. Blood transfusion.
- Correct underlying cause: i.e. bleeding.

- **Erythropoietin stimulating agents (ESA)**
  - Commonly used ESA are epoetin and darbepoietin.
  - Should use the lowest possible dose to maintain minimum level of haemoglobin, i.e., 10 g/dl.
  - There is evidence suggesting that the mean time for haemopoietic response to ESAs is between 1 - 2 months. Therefore, ESAs should be continued for a minimum of 2 months before diagnosing failure of response.
  - Complications of ESAs include an increased risk of thromboembolic events. Also, there's a controversy on tumour progression.

- **Micronutrients**
  - 150-200 mg of elemental iron is required. Oral iron is poorly tolerated, and prognosis should be considered before commencement.
  - Parenteral iron is useful for patients who are intolerant of oral iron, have intestinal malabsorption issues, and those who may be losing iron more quickly than which can be

replaced with oral supplementation. Commonly used parenteral iron preparations are iron sucrose and iron dextran. However, the calculated total dose need to be given in divided doses which require prolong admission or several visits to a day unit. There is a potential risk of allergic reaction/anaphylaxis although this is hardly seen with the currently available preparations.

- Folic acid, B12 supplementation: folic acid deficiency is a common finding in many conditions, and supplements (Folic acid 400mcg- 1mg PO daily/ Vitamin B12 1mg IM monthly) should be given for 4 months.

- **Blood transfusions**

  - The most common indications are symptomatic anaemia and continuous bleeding.
  - In patients without acute coronary artery disease, red cell transfusion is generally unnecessary until haemoglobin levels approach 70–80 g/L as long as there is no evidence of bleeding or symptoms of hypoxia.
  - Patients with acute anaemia are more likely to be symptomatic and this occurs when there is an abrupt drop in RBCs, most often by haemolysis or acute haemorrhage.
  - Chronic anaemia is generally due to gradual decline in RBC as in nutritional deficiencies, chronic diseases and the patients are usually asymptomatic due to cardiovascular adaptation to the hypoxia.

2. Neutropenia

Introduction:
Neutropenia is defined as an absolute neutrophil count (ANC) less than 1500 cells/µl while a count less than 500 cells/µl is considered severe neutropenia. Patients with neutropenia are at high risk of developing severe bacterial as well as fungal infections which can be life-threatening.

Management of infections is critical to both survival and quality of life of patients with terminal disease. Majority of these patients will eventually succumb to infections. Investigation and management should be tailored to the overall goal and care of the patient.

Causes of neutropenia:

- Myelosuppression due to chemotherapy/radiotherapy.
- Disease infiltration of the bone marrow by haematological and non-haematological malignancies.
- Intrinsic bone marrow failure: e.g., myelodysplastic syndrome (MDS), hypoplastic/aplastic anaemia.

Factors such as presence of indwelling foreign objects (E.g., urinary catheters, cannulae) and immobility increases the susceptibility to infections in these patients.

Common types of infections seen in patients in palliative care:

- Urinary tract infections.
- Orthostatic pneumonia.
- Surgical site infections.

Management:

- Early detection of infections/sepsis.
- Management of febrile neutropenia.

The decision of management depends on the stage of disease and the patient's wishes. If prolongation of life is considered appropriate, the extent of investigations and management should be discussed.

- Investigations: FBC, liver functions, serum electrolytes, serum creatinine, appropriate cultures, chest X-ray
- Sepsis screen: CRP, urine and blood culture, cultures from any other suspicious focuses.

- Empirical antimicrobial treatment using anti-pseudomonal broad, -spectrum antibiotics must be started immediately in neutropenic patients with sepsis. Eg: piperacillin/tazobactam or meropenem +/- aminoglycoside +/- antifungal

- Management should be guided by clinical microbiological test results whenever possible.
- Oral or IV antibiotics: high-risk patients with febrile neutropenia should be hospitalized for intravenous antibiotic therapy
- Treatment should be continued for an appropriate duration for the site of infection and the identified organism.
- If fever persists or new symptoms of infections develop, additional investigations and alterations in the antimicrobials may be necessary.
- G-CSF is not generally used to raise neutrophil counts as a prophylactic measure in a palliative care setting.

Prevention of infections

- Skin care
- Prophylactic antibiotics: patients with absolute neutrophil count (ANC) <100 cells/µl for more than 7 days can be considered for prophylactic antibiotics.

3. Bleeding

Acute and chronic blood loss is common in patients in palliative care. Bleeding in these patients can range from slow capillary oozing from malignant wounds to catastrophic haemorrhages. Any form of bleeding can be distressing to the patient as well as care-givers. Advanced planning is necessary for all patients with the potential to bleed, as this symptom is a source of considerable distress for patients, members of the family as well as staff and providers of terminal care.

Causes of blood loss:

- Invasion of malignant tumour of a blood vessel or gastric erosion: e.g., malignancies in the gastrointestinal tract or urinary tract.
- Thrombocytopenia: E.g., due to marrow failure, advanced liver disease or hypersplenism.
- Overdose of an anticoagulant or antiplatelet therapy with a very low platelet count: e.g., warfarin, heparin, NSAIDs.
- Coagulation disturbances: E.g., disseminated intravascular coagulation (DIC), primary fibrinolysis, liver disease (liver failure or metastasis).

Patients at risk of bleeding:

- Severe thrombocytopenia (<than 20,000)
- Large head and neck carcinomas
- Large centrally located lung cancers
- Refractory acute and chronic leukaemia (M3 AML)
- Myelodysplasia
- Severe liver disease
- Myeloproliferative disorders
- Recurrent rectal carcinoma
- Hepatocellular carcinoma
- Metastatic tumours (choriocarcinoma, melanoma, renal cell carcinoma)
- Patients with advanced malignancy on oral anticoagulants
- Bone marrow transplant patients with graft-versus-host disease (GVHD)
- Treatment with high-dose radiation therapy
- Metastatic liver disease

Management:

1. **Planning for a bleeding event**

- Providing dark towels and dark basins to make blood loss less evident
- Instructing caregivers on how to apply pressure if there is a specific bleeding site
- Instructing caregivers how to position a patient with massive haemoptysis or hematemesis
- Providing sedatives for treatment of anxiety, e.g., midazolam

2. **Local measures**

- Compression dressings and packing
- Topical haemostatic agents: fibrin sealants, gelatine foams, adrenaline, tranexamic acid
- Astringents: silver nitrate, Alum
- Radiation therapy
- Palliative embolization
- Endoscopy: ligation, sclerosing agent, cauterization, balloon tamponade
- Surgical intervention

3. **Systemic measures**

- Antifibrinolytic agents: tranexamic acid IV or oral is an effective therapy to control and prevent bleeding.
- Vitamin K: indicated in suspected vitamin K deficiency to improve haemostasis.
- Platelet transfusion
- Plasma products: fresh frozen plasma, cryoprecipitate
- DDAVP (1-desamino-8-D-arginine vasopressin): in patients with bleeding who have treatment-related thrombocytopenia or thrombocytopenia due to hematologic malignancy, desmopressin can minimize the need for transfusions.

4. Thrombosis

Introduction:

Thrombosis is the formation of a blood clot within the vascular system or heart, due to changes in the blood flow, damage to the endothelial surface or constituents of blood. In palliative care, the commonest thrombosis is venous thromboembolism (VTE). However, arterial thrombosis also has an association with cancers.

VTE includes deep vein thrombosis (DVT) and pulmonary embolism (PE). It occurs in 1 in 1,000 adults. The risk is increased with advanced age, reduced mobility and concurrent chronic illness including cancer. Approximately 15% of patients with malignancy develop symptomatic VTE, 15–20% of VTE have cancer, and about 10% with idiopathic VTE will develop cancer within a year.

Malignancy is associated with a higher rate of anticoagulant failure and a two to six-fold higher rate of major bleeding. Patients suffering from malignancy and thrombosis have a shortened life expectancy.

Pathophysiology of thrombosis in the presence of a malignancy is multifactorial. Presence of large lymph nodes or tumours causing local compression, obstruction of veins, lymphatics, arteries, and paralysis due to spinal cord compression, immobilisation, hospitalisation and complications of cancer therapy, indwelling catheters can contribute to venous stasis. Many chemotherapeutic agents: e.g., asparaginase, surgical interventions, and central venous access can contribute to endothelial injury. Certain malignancies give rise to procoagulant changes in the blood. For example, an increase in circulating levels of tissue factor, and thrombogenicity often depends on tumour type and stage, prostatic carcinomas, adenocarcinomas, pancreatic carcinomas.

Symptoms and Signs:

- Dyspnoea is the most common symptom of PE, while swelling of the leg occurs in DVT.
- It's important to know in advance cancer and palliative setting various other causes may give rise to similar symptoms.

Diagnosis:

- D-dimer has limited value in predicting VTE in the presence of malignancy and palliative care. It is because it is often high due to several other reasons. Although d-dimer values play an important role in the diagnosis of VTE with a negative predictive value of close to 100%, it has little or no role in the palliative care setting as there are many confounding factors that contribute to a high d-dimer such as inflammation.
- The definitive confirmatory investigation for DVT and PE is compression ultrasonography; and for PE computed tomography and pulmonary angiograph. Both investigations are relatively easy to access and well tolerated by patients.

Management

- The aim is to relieve symptoms and improve quality of life.
- In malignancy and palliative care, choice of anticoagulant should be tailor-made to the patient. It is paramount to consider bleeding risk, presence of thrombocytopenia, renal impairment, life expectancy and other comorbidities, requirement of frequent monitoring, mode of administration and patient preference.
- Therapeutic options available include Low molecular weight heparin (LMWH), Unfractionated heparin (UFH), warfarin and direct oral anticoagulants (DOACS). At present, the mainstay of treatment consists of administering a fast-acting agents such as intravenous (IV) UFH or subcutaneous (SC) LMWH.
- LMWH -This is frequently followed by initiation of warfarin to obtain a target INR of 2–3 as an ongoing maintenance

therapy. An overlap of approximately 5–7 days is required between parenteral and oral medications as there is a delay in the onset of anticoagulant effect of warfarin, until therapeutic range is achieved. More recent data supports ongoing use of LMWH rather than warfarin in cancer patients, particularly in those who are on concurrent chemotherapy as well as those with metastatic liver disease. Regular monitoring of INR to maintain warfarin within the therapeutic range, frequent visits to hospital, and difficulties in venous access with patients with terminal disease and patients who have received multiple cycles of chemotherapy can be extremely difficult.

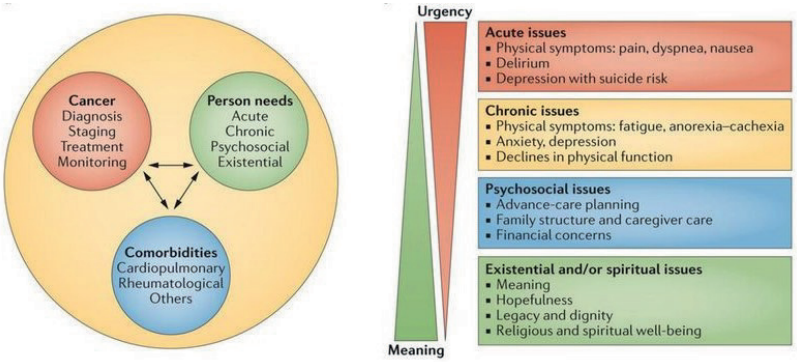
- Duration of anticoagulation should be decided after considering, stage of malignancy, risk of bleeding, life expectancy and wishes of the patient.
- However, a minimum of 6 months is recommended after an acute VTE.

Prophylaxis of VTE

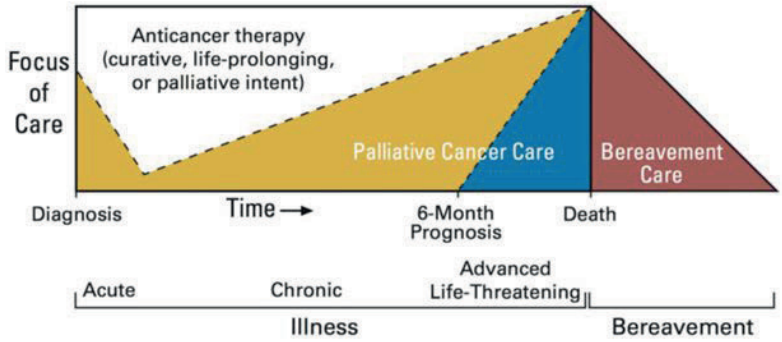
Prophylaxis of VTE should be considered in palliative care when short term immobilization and hospitalization is required especially after surgery. This will improve the quality of life.

B. Palliative care in haematological malignancies

Palliative care is no different in haematological malignancies as in any other malignancies. As haematological malignancies are more prevalent in the elderly, in which other comorbidities also concurrently exists, improving quality of life becomes more important than cure.



Even though management is initiated with a curable intent, due to intolerability of chemotherapy, other comorbidities, serious side effects of treatment and treatment refractoriness, chemotherapy is often interrupted. As a result, a paradigm shift in management occurs, where treatment continues with palliative intent with or without chemotherapy. Therefore, combined standard care in haematology and palliative care should be considered early in the course of the disease for all patients with haematological malignancies.



In comparison to general palliative care, cancer palliative care has its characteristic problems. These are,

1. Cancer specific symptoms & complications

Haematological malignancies are characteristically associated with symptoms that occur due to cytopenias, such as bleeding due to thrombocytopenia, fatigue due to anaemia and recurrent bacterial infections due to neutropenia. In addition, bone pain, fever, poor appetite, lethargy and generalized ill-health are common, troublesome symptoms that aggravate the patient's poor quality of life.

2. Supportive care for anti-cancer treatment side effects alleviation or prevention

Anti-cancer treatment is invariably associated with numerous side effects such as nausea, vomiting, poor appetite, mucosal ulcers, sore mouth, dry mouth, constipation, etc. Supportive care to alleviate or to prevent these side effects is an important aspect of management of these patients in order to maintain quality of life. These may further aggravate deficiency anaemias due to lack of vitamins as well as occult blood loss due to gastritis, and cancer cachexia.

3. Cancer-specific communication processes

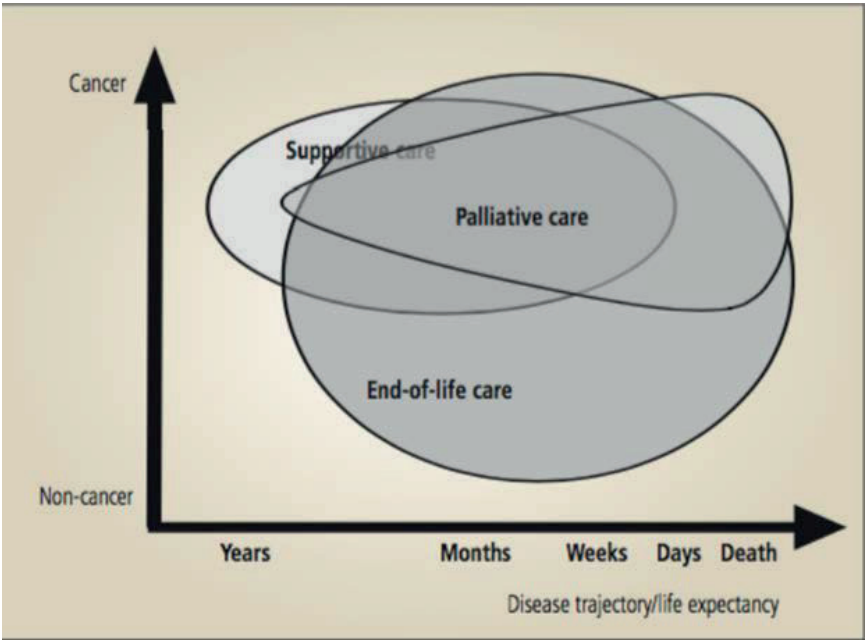
Living with malignancy needs extra care in communication. Beginning from breaking bad news, up to the end-of-life care, careful, sensitive approach in communication is required with patient as well as the family with the consent of the patient. A multi-disciplinary team is best with family members, care givers to support the patient as well as each other.

4. Anti-cancer interventions to improve control of symptoms

In haematological malignancies, anti-cancer treatment per se can provide symptom relief, e.g., local radiotherapy for plasmacytomas causing cord compression or for a single painful lytic lesion.

Therefore, sometimes anticancer treatment itself is useful in palliation.

It is clear, that anti-cancer treatment and palliation goes hand in hand from the time of diagnosis of a haematological malignancy. Therefore, haematologists have a significant role not only in treating the malignancy but also in providing palliative care to their patients. The involvement of the palliative care team is equally important in fulfilling a patient's needs at each stage of management.



Following are the commonest haematological malignancies encountered with palliative care issues.

I. Acute leukaemias

In general, acute lymphoblastic leukaemias in children has an excellent prognosis. However, in adults, prognosis of acute

leukaemia depends on many factors. The commonest palliative care issues encountered in acute leukaemias are related to cytopaenias; e.g., bleeding, anaemia and recurrent infections, pain, side effects of chemotherapy such as nausea, vomiting, poor appetite etc. Ultimately some such leukaemias may reach a treatment-refractory stage in which end of life care, relief of symptoms, and pain relief due to infiltration of critical organs will be priority.

II. Multiple myeloma

Multiple myeloma is a malignant disorder of plasma cells that is incurable. The disease itself may cause fractures, renal impairment, and single painful bony lesions. Transplant-ineligible elderly patients need continuous chemotherapy for disease control. Even though these treatment options are not profoundly cytotoxic, side effects may lead to peripheral neuropathy, somnolence, poor appetite, constipation or diarrhoea, mood changes and cytopaenias.

III. Myeloproliferative neoplasms (MPNs)

The most common myeloproliferative neoplasms are chronic myeloid leukaemia (CML), polycythaemia vera (PV), essential thrombocytosis (ET), primary myelofibrosis (PMF) and chronic myelomonocytic leukaemia (CMML). These patients too can develop cytopenias necessitating transfusions. Further, some MPNs like PV, ET and MF are more prone to develop thrombosis. MPNs in the long term have the ability to transform in to acute myeloid leukaemias. When it does so, will behave as high risk acute myeloid leukaemia.

IV. Myelodysplastic syndrome (MDS)

MDS is a group of bone marrow failure disorders characterised by clonal cytogenetic abnormalities. These patients present with

cytopenias and need transfusion support. Specific treatment also can cause transient cytopenias and other side effects such as nausea and vomiting. Like MPNs, MDS also transforms into acute myeloid leukaemias with necessitating palliative care as an integral part in its management.

V. Lymphomas

Lymphomas are malignancies that arise within the lymphatic system. It can be classified as low- or high-grade. Patients will experience cytopenias at presentation or during treatment and will require transfusion support. Some of these patients may progress to treatment refractory disease which will eventually require relief of symptoms, improve quality of life and end of life care.

References:

1. Auret K et al. *Int Med Journal.* 2003; 33: 566 571
2. Cherny N, Fallon M, Kaasa S, Portenoy R K, Currow D C; Oxford Textbook of Palliative Medicine:2017
3. Cherny NI, Catane R, Kosmidis P; ESMO Taskforce on Supportive and Palliative Care. ESMO takes a stand on supportive and palliative care. *Ann Oncol.* 2003 Sep;14(9):1335-7.
4. Dunn A. et al. Anemia at the end of life: prevalence, significance, and causes in patients receiving palliative care. *Journal of Pain and Symptom Management*, Volume 26, Issue 6, 1132 - 1139
5. Geist, M. J. P., Kessler, J., Frankenhauser, S., & Bardenheuer, H. J. (2017). Bleeding Control in Palliative Care Patients With the Help of Tranexamic Acid. *Journal of Palliative Care*, 32(2), 47–48. doi:10.1177/0825859717731701
6. Hui D, et al., Indicators of integration of oncology and palliative care programs: an international consensus. *Annals of Oncology* 2015, 26(9): 1953 1959
7. Kochanek, M., Schalk, E., von Bergwelt-Baildon, M., Beutel, G., Buchheidt, D., Hentrich, M. Böll, B. (2019). Management of sepsis in neutropenic cancer patients: 2018 guidelines from the Infectious Diseases Working Party (AGIHO) and Intensive Care Working Party (iCHOP) of the German Society of Hematology and Medical Oncology (DGHO). Annals of hematology, 98(5), 1051–1069. doi:10.1007/s00277-019-03622-0
8. Noble S. Venous thromboembolism and palliative care. Clin Med (Lond). 2019;19(4):315–318. doi:10.7861/clinmedicine.19-4-315.
9. Prommer, E. (2005). Management of bleeding in the terminally ill patient. *Hematology,* 10(3), 167–175. doi:10.1080/10245330500093237
10. Radbruch L, et al., *European Journal of Palliative Care*, 2009; 16(6); 278-289.
11. WHO report "Strengthening of palliative care as a component of integrated treatment throughout the life course" (2013)
12. Zhu, N., & Wu, C. (2015-03). Anaemia, cytopenias, and thrombosis in palliative medicine. In Oxford Textbook of Palliative Medicine. Oxford, UK: Oxford University Press.

CHAPTER 18

Palliative Wound Care

Malignant Ulcers and wounds

Malignant cells infiltrating the cutaneous tissue and vasculature (due to primary or metastatic disease) can result in necrotic malignant wounds. Malignant wounds occur in ~10% of patients with metastatic disease, most often in the last six months of life. Malignant wounds can affect patient's activities of daily living and self-image and confidence.

Palliative care patients with malignant wounds may not be tolerant of traditional treatment methods including surgical debridement and closure., hence requiring different approaches in management focusing on quality of life.

A malignant wound may present with;

- Pain,
- Odour, (and infection)
- Exudate and
- bleeding that interfere with quality of life.

Pain

Individual patients pain depends on the location of the wound, the amount of tissue and nerve damage and the person's psychological factors.

Management

Ongoing pain management may require regular systemic opioids to control background pain. Most wounds cause severe neuropathic pain needing neuropathic pain agents

- (Refer to the chapter on pain management)

Dressing changes could be particularly painful. Breakthrough (immediate release) analgesia should be administered prior to the dressing changes, with adequate time allowed for the analgesic to have the desired effect (~30 minutes for most immediate release opioids).

Despite having limited evidence, topical opioids and topical local anesthetics are used in malignant wound care dressing management.

- Injectable morphine can be mixed with most gels, or morphine could be crushed and mixed with gel as topical application.

Odour

Wound odour is a result of tissue necrosis and bacterial growth especially anaerobic and certain Gram-Negative (e.g. pseudomonas) organisms. Managing odour is extremely important for the quality of life of the patient and the family. Inquiries on wound odour from patients and the family should be taken into consideration as health care team can become desensitized to the odour.

Management:

Wound cleaning and dressings for exudates/discharge is important in reducing odour.

- gently irrigate the wound with warmed normal saline for 10-15 minutes at site
- Use the dressings that support autolytic debridement

Measures to absorb odour / Decrease odor in the environment

- Activated charcoal dressings
- Peppermint or other aromatic oils placed in the room
- Room ventilation

Routine swabbing of malignant wounds is of little value unless rapidly progressive infection is suspected.

- Topical antimicrobials: Metronidazole gel, opened capsules (200mg) , crushed tablets (200mg) or injectables (0.5%) can be applied on the wound with each dressing change.
- Silver dressings: Silver dressing has antimicrobial action.

Exudate / Discharge

Increased capillary permeability of the malignant wound vasculature causes excessive exudates. Some patients may develop surrounding dermatitis due to ongoing wound exudates.

Management:

Dressings should be selected best to absorb and contain exudate.

- Foams
- Gauze
- Absorbent cover dressings that contain exudates
- Menstrual pads (excessive exudates): can be effective as they are highly absorptive and due to their availability.

The optimum frequency of dressing changes will depend on the amount of exudate (generally1-2 times a day).

Bleeding

Malignant tissues may be very friable and bleed with minimal manipulation especially during wound dressings.

Management:

Maintaining a moist wound bed

- Use warmed normal saline irrigation to moisten the dressing and prevent trauma during dressing changes.

Topical Hemostatic Agents

- Calcium Alginates
- Tranexamic acid (oral/ injectable) 500mg can be applied on the wound with each dressing change.

Controlling bleeding

- If bleeding does occur, apply direct pressure for 10-15 minutes.
- Local ice packs can also assist in controlling bleeding

Radiotherapy

- Palliative course of radiotherapy can be considered for radiosensitive tumours.

Tumor eroding into a major blood vessel especially in head and neck malignant wounds can result in significant or catastrophic bleeding. (refer to catastrophic bleeding management)

Pressure Ulcers

Palliative care patients often have or are at risk for pressure ulcers due to multiple risk factors including impaired mobility, increased skin friction, lack of nutrition and reduced skin perfusion as a part of multi organ failure.

Management

Pressure Redistribution with frequent turning allowing better tissue perfusion, is the best method to prevent and relieve pressure ulcers.

- If patient experiences pain during interventions, patient may require Immediate release opioids 20 to 30 minutes prior to turns.
- Consider applying a foam dressing to bony prominences
- Avoid positioning the patient on an area of erythema whenever possible.

Consider using a skin moisturizer to hydrate dry skin.

- But avoid vigorous skin massages over the areas risk of pressure ulcers.

References

1. Langemo DK, Anderson J, Hanson D, Hunter S, Thompson P. Managing fungating wounds. Advances in skin & wound care. 2007 Jun 1;20(6):312-4.
2. WRHA Malignant Wound Clinical Practice Guideline: http://www.wrha.mb.ca/extranet/eipt/files/EIPT-013-007.pdf
3. Young T. Caring for patients with malignant and end-of-life wounds. Wounds UK. 2017 May 2;13.

CHAPTER 19

Nutrition and Hydration in Palliative Care

Introduction

Oral intake of both food and fluids can diminish significantly at end of life, combined with weight loss and muscular weakness. Nutrition issues can arise due to reduced food intake and digestion, increased loss of nutrients or altered energy utilization or a combination of all these factors. This often takes place in the context of the anorexia-cachexia syndrome which is characterized by progressive lean muscle loss (with or without fat loss), that cannot be reversed by conventional nutritional therapy. The muscle loss is mainly due to metabolic abnormalities, particularly in protein and energy balances. Nutrition support is a recognized element of palliative care which often offers physical, psychological and social benefits to patients and families.[1] Apart from clinical benefits, there are also other comfort and ethical reasons for nutrition support.

Patients must receive food and hydration, but the emphasis should be on quality of life and symptomatic relief rather than active nutritional therapy. This guidance focuses specifically on the treatment of nutrition and hydration issues. From a palliative point of view, in the final days, the decision-making process must consider patient comfort as the primary outcome and provide treatment accordingly. A discussion by the management team with the patient (if possible), family and staff is necessary and consideration of the patient's priorities and preferences are paramount. During the end of life process, majority of patients do not experience hunger, and small amounts of food and fluids, offered whenever the person wants, or treating dry lips and mouth is adequate. Family members must be made to understand this.[2]

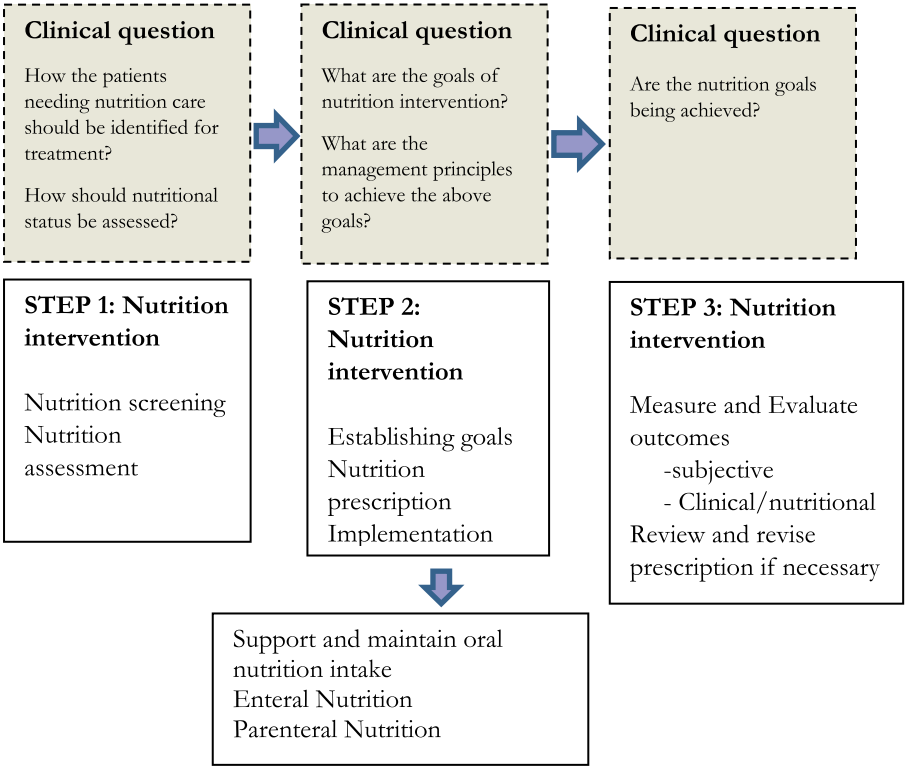
Emphasis is on quality of life and symptomatic relief rather than on active nutritional therapy

Objective

The objective of this chapter is to gain knowledge and understanding regarding assessment of nutritional status, identifying goals of nutrition intervention and methods for providing nutritional support in the setting of palliative care.

Management

Framework for nutrition care process



STEP 1

1. Nutrition Screening: [3]

Identify "at risk" patients for referral/further support by the criteria given below, or, a nutrition screening tool. In an adult patient, criteria for malnutrition and provision of nutrition support are defined by any one or a combination of the following:

- BMI < 18.5 kg/m^2
- unintentional weight loss > 10% in last 3-6 months
- BMI < 20kg/m^2 and unintentional weight loss >5 % in last 3-6 months (NICE 2006)

Or

- Generic screening tools such as Malnutrition Universal Screening Tool (MUST) can be used.

Practice Tips

- Nursing staff can be trained to implement screening.
- Incorporate routine screening into admission forms.
- Repeat nutrition screening during treatment (every 2 weeks) for patients initially screened at low risk

2. Nutrition Assessment:

A comprehensive assessment should be done and should include the following:

Parameters	**Assessment (should be contextual to situation)**
Medical history	Symptoms (specific attention to gastrointestinal symptoms; appetite and taste changes, odyno/dysphagia, presence of pain,

	current treatment and medication (specifically anti-emetics, laxatives, analgesics, appetite enhancers, complementary medicines).
Dietary intake	Assess dietary intake through a 24 hour recall: include use of supplements, food likes and dislikes
Clinical examination	Anthropometry (weight and height, fat mass assessment if necessary), particular attention to oral cavity; presence of inflammation, glossitis, angular stomatitis, mouth sores, lesions, teeth, hydration status.
Biochemistry (if indicated)	Blood glucose, haemoglobin, serum albumin, c- reactive protein, serum electrolytes

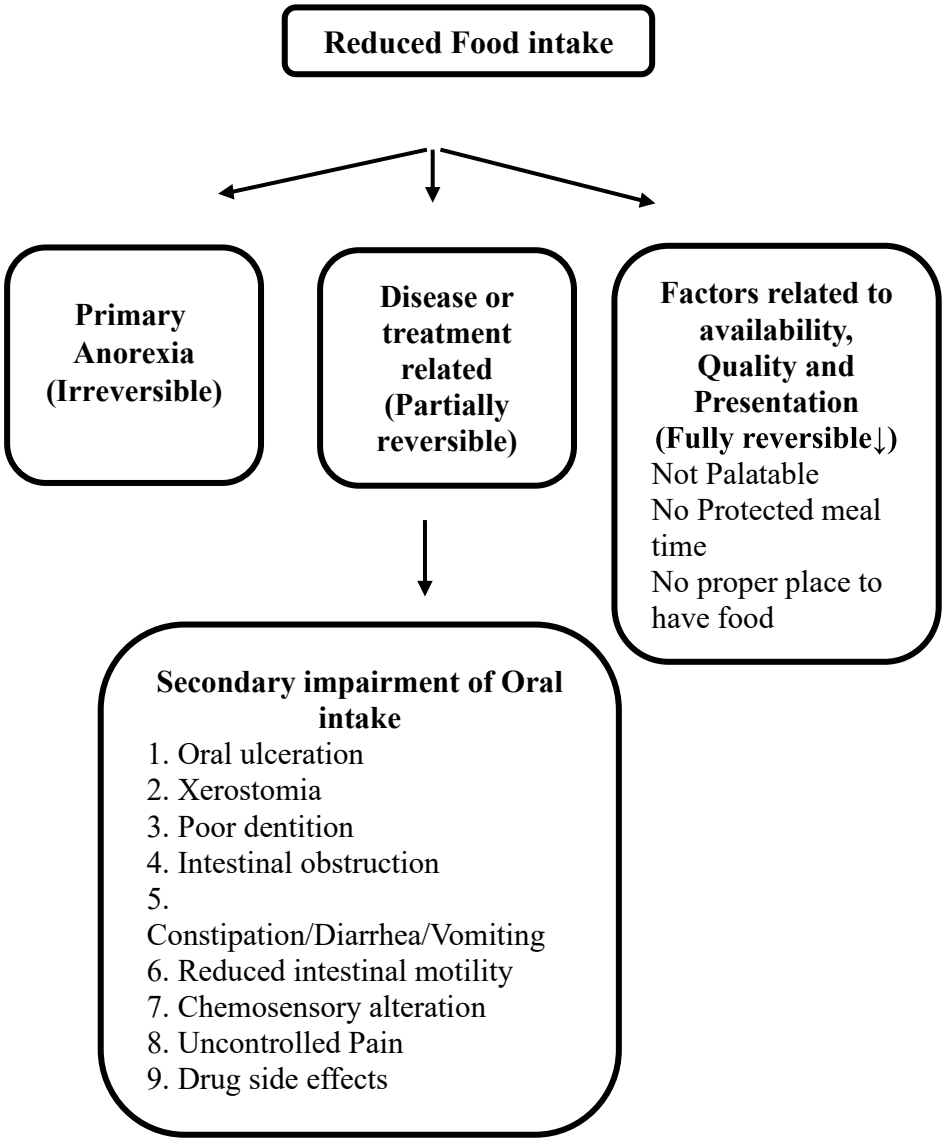
An appropriately validated and reliable nutritional assessment tool should be used.

- Malnutrition Universal Screening Tool (MUST)[4]
- Malnutrition Screening Tool (MST)[5]
- Patient Generated Subjective Global Assessment (PG-SGA)[6]

Practice Tips

- Identify cachexia: Cachexia is characterized by debilitation such as fatigue, muscle wasting, loss of body fat, inflammation and loss of appetite.

When a patient has reduced food intake always look for reversible causes[7].

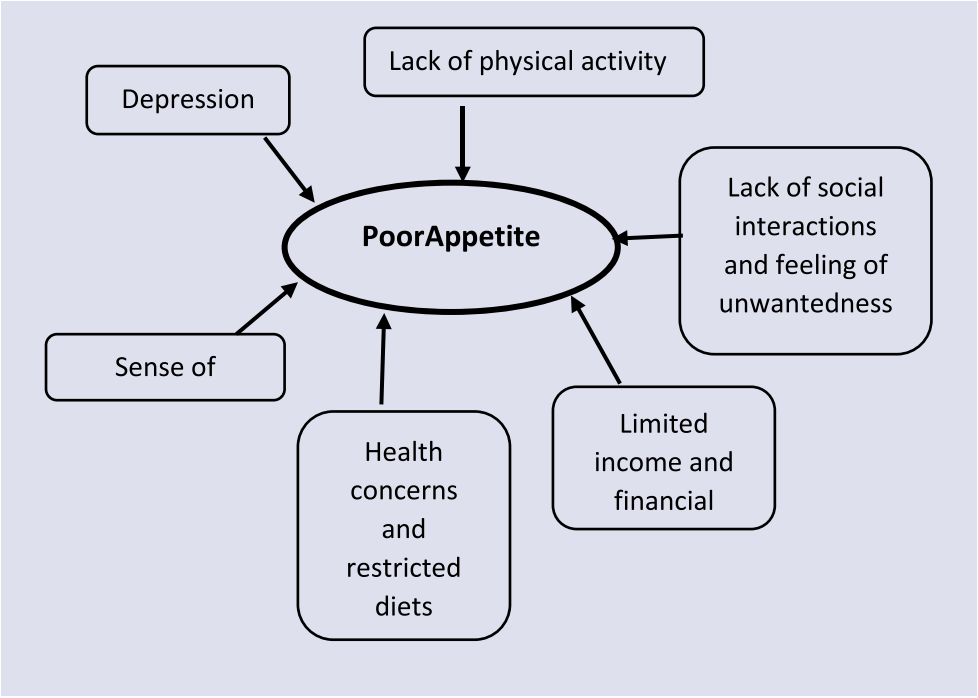


Practice Tips[8]

Use the following strategies to manage taste changes, early satiety, and aversion to food smells

- *Dry mouth and/or swallowing problems - modify texture as required*
- *Nausea / vomiting - increase carbohydrates & cool clear liquids*
- *Anorexia / early satiety - food preferences, comfort foods, small frequent meals, supplements*
- *Xerostomia - sour sweets, ice chips, cold foods, stews*
- *Taste and smell changes- lukewarm bland foods*
- *Use ice chips, cold water or juice to promote fluid intake*

Psychological causes also can contribute to reduced food intake. Timely psychiatric advice and psychological counselling can not only improve food intake but also overall wellbeing of the patient and the family.[9, 10]



Understanding the patient is equally important as understanding the disease[11].

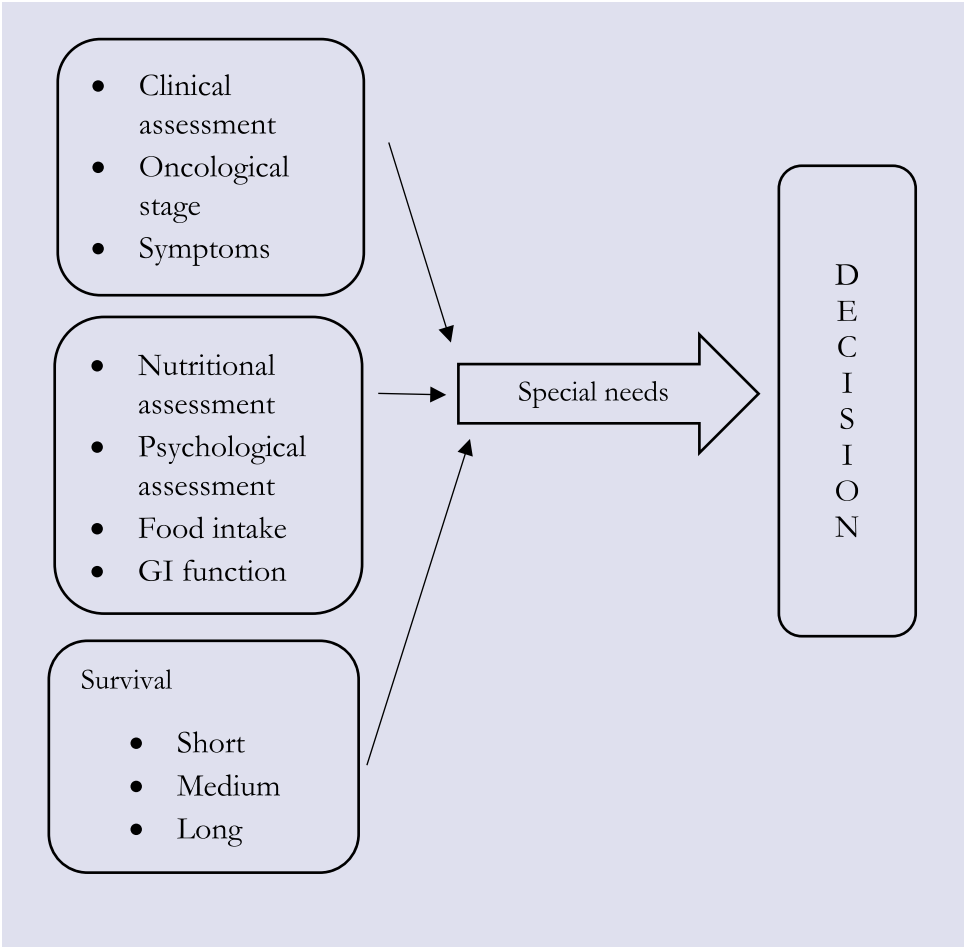
- Food has many symbolic meanings – understand the food habits of the patient
- It establishes and maintains relationships.
- Food is used to express love, affection and closeness of relationship
- Represent social status
- Food represents the cultural, ethnic and religious characteristics
- Food is used to celebrate occasions
- Food is a mean of reward or punishment
- Forcing a patient to eat does not allow the patient to live longer or feel stronger but may instead cause discomfort rather than pleasure

STEP 2

Establishing nutrition goals: Make decisions based on type and stage of illness, duration, patient's, and family's wishes.

- Nutrition in early stages of the disease – Better and more complete nutrition is required to help the patient to cope up with the metabolic demand of illness, prevent infection, improve tissue repair and general wellbeing

- Nutrition in late stages of the disease – more focus of maximizing the pleasure and enjoyment of food and minimizing the food related discomfort[9].


Clinical assessment
Oncological stage
Symptoms
Nutritional assessment
Psychological assessment
Food intake
GI function
Survival
Short
Medium
Long
Special needs
DECISION

Nutritional Support in Palliative care

Routes of Nutritional support

I. **Oral route –** Preferred route in the absence of no oral and swallowing problems, dysphagia, vomiting, intestinal obstruction or gastrointestinal pathology which needs bowel rest. It gives the 'pleasure of eating' and feeling of satiety in addition to nutritional supplementation.

II. **Oral nutritional supplements –** Oral nutritional supplements can be used when oral intake is not sufficient to maintain nutrition. This is especially useful when there is disease related anorexia, changes in smell or taste, painful or dry mouth, breathlessness, or fatigue on eating and poor oral intake due to psychological causes.

III. **Enteral nutrition –** Enteral feeding is used in patients with oral/oesophageal problems or swallowing difficulties but have normal gastro-intestinal function. Using a feeding tube all or part of the patient's caloric requirement is delivered into the stomach or the small intestine. Enteral route is better than parenteral route as it is physiological, less expensive and has lesser complications. It also reduces the risk of bacterial translocation.

IV. **Parenteral Nutrition** – Intravenous administration of fluids and nutrients in patients with impaired food intake, digestion and absorption. It is also used in conditions when complete bowel rest is required like in intestinal failure, short bowel syndrome, intestinal obstruction or gastro-intestinal fistulas.

V. **Artificial Hydration** – Provision of water and electrolytes by any other route other than mouth. Artificial hydration using a sub-cutaneous butterfly cannula can be used when

all other methods of nutrition and hydration is not possible as the last resort in terminally ill patient.

1. Nutrition prescription and implementation:

Weight stabilization as a goal: energy requirement can be calculated through use of equations. Energy and protein requirements for weight stabilization are approximately 120 kJ/kg/d and 1.4 g protein/kg/d. Fluid needs can usually be met by giving 30–35 ml/kg bodyweight although allowance must be made for excessive losses from drains or fistulae.

Categories of nutrition support

(i) Support and maintain usual nutrition intake with dietary counselling.

Wherever possible, this is the best choice, especially when the GI system is not compromised significantly. The strategy should be to ensure correct quantity and balance of required nutrients. Provide guidance on small frequent meals and drinks, individual preferences, adapted consistency of foods, flexible timetables and family involvement. Oral nutritional supplements can be added if necessary.

Promote good sources of energy and protein in the diet and include foods from all 5 main food groups; grains and cereals, starchy vegetables, meat, fish and poultry, fruits, oils and fats. If vegetarian ensure adequate alternative sources of protein such as legumes. However, encourage the patient to eat any foods that they desire.

- If intake is reduced due to taste changes emphasize good oral hygiene and try different recipes and smaller portions.

- For patients with chewing and swallowing difficulties, ensure texture modified diets e.g. minced or pureed foods, mashed foods, thick soups, chilled foods, low spices.
- Multivitamins, oral nutrition supplements: consider interactions with regular medication prior to prescription.
- N 3 polyunsaturated fatty acids may stabilize weight loss and improve quality of life[12].

(ii) Artificial nutrition and hydration

Artificial nutrition and hydration include

- Oral nutrition supplements
- Enteral nutrition
- Parenteral nutrition
- Artificial hydration

The ethically and legally accepted view is that artificial nutrition and hydration, whether delivered parenterally or through the gastrointestinal tract via a tube (including nasogastric tubes), is a medical intervention[13]. Like other interventions, it should be evaluated in light of the patient's clinical circumstances and goals of care. Evidence from literature does not show any improvement in quality of end-of-life situations with artificial support of nutrient intake.

Ethical principles of artificial nutrition in palliative care[14]

Prerequisites for artificial nutrition and hydration

I. An indication for medical treatment
II. Definition of the therapeutic goal to be achieved
III. The will of the patient and his or her informed consent

Ethical principles

I. **Autonomy** – a competent patient has the right to refuse any intervention after adequate information even if this refusal leads to death. However, it should be differentiated from loss of appetite which is associated with severe depression in terminally ill patients.

II. **Beneficence and non-maleficence** – All the risks and benefits of the intervention should be carefully assessed before starting therapy. Overall benefit should be evaluated in regard to the disease, quality of life, psychological and spiritual wellbeing. Prolonging the life should not be the focus. Any disproportionate treatment should be avoided. The need for continuous nutrition must be regularly reviewed in relation to patient's condition.

III. **Justice** - All patients have the right to receive the best available care without discrimination. Interventions which are futile and would only prolong the suffering should be avoided. When the resources are limited transparent and ethically appropriate criteria should be used in resource allocation among patients

Enteral route:

This is the first choice of support essentially for people without GI tract problems, but unable to feed or swallow adequate amounts orally[15].

Methods of providing enteral nutrition

Short term feeding

a) Orogastric tubes
b) Nasogastric tubes
c) Nasojejunal tubes

Long term feeding

d) Percutaneous endoscopic gastrostomy tubes (PEG) or jejunostomy (PEG –J) tubes
e) Radiologically placed percutaneous gastrostomy tubes
f) Surgically placed gastrostomy or jejunostomy tubes

Common problems with naso-gastric tubes

- Misplaced tubes
- Blockage
- Recurrent displacement
- Local irritation of the stomach and oesophagus which can result in upper gastrointestinal bleeding

Displaced naso-gastric tubes can cause life threatening aspiration. It is important to make sure the tube is in the stomach after insertion.

Methods that can be used to check the position of naso-gastric tube

- Chest X ray is the best method. NG tube should cross the diaphragm and the distal end should be in the stomach cavity.
- Auscultation is not reliable

- Examining the gastric aspirate for pH – If the pH value of the aspirate is <5 it indicates the distal end is in the stomach. But if the patients has been on long term proton pump inhibitors pH can be higher even if the distal end of the tube is in the stomach.

It is important to check the position of the naso-gastric tube before each meal by aspiration and checking for gastric contents.
Applying a nasal bridle would prevent repeated displacement of naso gastric tube.

Naso-Jejunal Tubes

Naso-jejunal tubes are used to give feeds directly to the jejunum. Main advantages are reduced risk of aspiration, useful in the presence severe vomiting, gastroparesis and when by passing the ampulla of vater is advantageous like in acute pancreatitis.

Naso-jejunal tubes can be inserted

- Endoscopically
- Radiologically
- Using an Enteral Access System (Not available in Sri Lanka) E.g. Cotrack system

Main disadvantage of Naso-jejunal tubes is recurrent displacement

Percutaneous Endoscopic Gastroscopy tubes (PEG) [16]

Placement of a PEG feeding tube is indicated for medium and long term feeding. Proper patient selection is the most important step in PEG tube placement. This should be done at a multi-disciplinary meeting with participation of the oncologist, palliative care

physician, gastroenterologist, speech and language therapist and the nutritionist considering not only the medical condition of the patient but also the wishes of the patient and the family. Patient and the family should be explained the procedure, the benefits, possible complications, after care and alternative therapies and should be given adequate time to make an informed decision. It is important to explain symptoms such as reflux and regurgitation will not improve with PEG tube insertion and it will not alter the course of the primary disease.

For a PEG tube to be inserted the patient should

- Be able to open the mouth adequately to place the mouth guard
- Be able to lie flat for approximately 20minutes without a breathing difficulty
- Be able to maintain oxygen saturation > 93% without oxygen
- Have normal blood coagulation

Contraindications for PEG feeding tube insertion

I. Ongoing infection (High CRP, Leukocytosis)
II. Severe coagulopathy (INR >1.5, Platelets <50000/mm3, APTT>50S
III. Hemodynamic instability
IV. Presence of Ascites
V. Peritonitis
VI. Gastric outlet obstruction if being used for feeding (Venting gastrostomy is used to decompress the bowel in malignant bowel obstruction)
VII. Severe gastroparesis (if used for feeding)
VIII. Marked peritoneal carcinomatosis
IX. Interposed organs (liver, colon) and intrathoracic stomach
X. Abdominal wall infection at the selected site of insertion
XI. Presence of gastric varices

Complications of PEG tubes

I. Leakage
II. Peri-stomal infection
III. Abdominal pain
IV. Fever
V. Pneumoperitoneum
VI. Bowel Perforation
VII. Buried bumper
VIII. Blockage of the tube
IX. Displacement

Radiologically Inserted Gastrostomy Tubes

Gastrostomy tubes can be placed with fluoroscopy guidance when endoscopic access is not possible or contraindicated

1. When oesophageal access of the stomach is not possible
    - Patient cannot open the mouth wide enough to hold the mouth guard
    - Malignant or benign oesophageal strictures
2. Head and neck cancers due to risk of seedling
3. Failed PEG

Jejunostomy tubes

Jejunostomy feeding tubes are better when long term post pyloric feeding is indicated. Jejunostomy tubes can be placed endoscopically, under fluoroscopy guidance or surgically.

Types of jejunostomy tubes

- PEG –Jejunostomy
- Direct Percutaneous jejunostomy need enteroscopy access with Laparoscopic assistance
- Transgwtric jejunostomy
- Surgical jejunostomy

Naso-jejunal tubes	Jejunostomy tubes
• Doesn't need anaesthesia or surgery – can be inserted even in ill patients • Can be used even in the presence of ascites, coagulopathy, and peritoneal metastasis and in patients undergoing peritoneal dialysis. • Easily removed and re-inserted • More suitable for short term feeding • Can get easily displaced or clogged or coiled back into stomach • Nasal pressure sores with long term tubes	• Suitable for long term jejunal feeding • For surgical placements patient should be fit for general anaesthesia and abdominal surgery. • Surgical jejunostomy should be used when endoscopic access is not possible due to oesophageal strictures or in morbid obesity when transillumination and/or digital indentation cannot be seen

Practice Tips

- Delivery - feeds can be administered via syringe, gravity feeding set or feeding pump. The method selected is dependent on the nature of the feed and clinical status.

- Type of feed:

Formula feeds: Usually contain 1.0 kcal/ml, with higher energy versions containing 1.5 kcal/ml. Polymeric feeds contain nitrogen as whole protein, the carbohydrate source is partially hydrolysed starch and the fat contains long chain triglycerides (LCTs). Predigested feeds contain nitrogen as either short peptides or, in the case of elemental diets, as free amino acids. Carbohydrates are hydrolysed starch and fats are as LCTs and medium chain triglycerides (MCTs). Disease specific feeds are available.

- A blended diet: Home-made everyday food blended to a smooth 'single cream' consistency can be given though there are concerns of tube blockage and diarrhoea.

- Duration of delivery: consider changes with disease progression, new symptoms

- If feasible, maintain even minimum *oral intake of fluids.*

Parenteral route:

If GI tract obstructed or if unable to digest and absorb, nutrition can be delivered via peripheral (if route is for < 14 days) or central vein (> 14 days via a large bore IV catheter). Risk of infection and condition of patient needs to be considered when making the decision to feed parenterally. Total parenteral nutrition or partial nutrition requirements can be delivered through this method. The amount and type of mixture depends on needs of the patient. Amino acids, fats, vitamins and other nutrients can be delivered.

Adverse effects include hyperglycaemia, refeeding syndrome, and metabolic acidosis. **Refeeding syndrome**[17] may occur within first 3-4 days of re-introducing nutritional support and is more likely when high calorie nutrition is rapidly introduced to malnourished persons. Other adverse effects include increased risk of complications, difficulties in home care and cost.

Practice Tips

- With any type of support, dietary counselling is essential. With enteral or parenteral feeding, train care giver to recognize risks and problem solving on minor

(iii) Pharmacological agents:

Appetite stimulants may increase intake, body weight, and quality of life, but they do not affect prognosis in the terminally ill. Reduced intake may be secondary to anorexia caused by reduced gastric emptying and a prokinetic drug (E.g. metoclopramide, domperidone) can enhance gastric emptying to allow more food intake. Corticosteroids may improve appetite and also provide a feeling of improved wellbeing for a few weeks. When lack of

appetite is a significant quality-of-life issue for a dying patient a trial of oral dexamethasone 2 – 4 mg daily is recommended. Progestational agents also (Megestrol) may reduce severe anorexia. Cannabinoids (medicinal cannabis) may increase appetite but the efficacy, route of administration and the doses required are still under investigation[18].

Refeeding syndrome can be defined as the potentially fatal shifts in fluids and electrolytes that may occur in malnourished patients receiving artificial refeeding (whether enterally or parenterally). These shifts result from hormonal and metabolic changes and may cause serious clinical complications. The hallmark biochemical feature of refeeding syndrome is hypophosphataemia. However, the syndrome is complex and may also feature abnormal sodium and fluid balance; changes in glucose, protein, and fat metabolism; thiamine deficiency; hypokalaemia; and hypomagnesaemia

References:

1. Amarya S, Singh K, Sabharwal M. Changes during aging and their association with malnutrition. Journal of Clinical Gerontology & Geriatrics.2015;6:78-84.
2. American Academy of Hospice and Palliative Medicine. Statement on Artificial Nutrition and Hydration Near the End of Life. http://aahpm.org/positions/anh
3. Arends J, Bachmann P, Baracos V, Barthelemy N, Bertz H, Bozzetti F et al. ESPEN guidelines on nutrition in cancer patients. Clinical Nutrition.2017; 36:11- 48.
4. David Hui, Maxine De La Cruz, Masanori Mori, Henrique A. Parsons, Jung Hye Kwon, Isabel Torres-Vigil, Sun Hyun Kim, Rony Dev, Ronald Hutchins, Christiana Liem, Duck-Hee Kang, and Eduardo Bruera. Concepts and definitions for "supportive care," "best supportive care," "palliative care," and "hospice care" in the published literature, dictionaries, and textbooks. *Support Care Cancer* 2013; 21(3): 659–685.
5. Druml C, Ballmer PE, Druml W, Oehmichen F, Shenkin A, Singer P et al. ESPEN guideline on artificial nutrition and hydration. Clinical Nutrition. 2016; 35:545-556.
6. eTG Complete. Australian Therapeutic Guidelines. Published by Therapeutic Guidelines Ltd. June 2019. https://tgldcdp.tg.org.au/viewTopic?topicfile=palliative-care-gastrointestinal-symptoms#MPS_d1e1583
7. Hearing SD. Refeeding syndrome. British Medical journal.2004;328 (7445):908-909
8. Ma G. Food, eating behavior and culture in Chinese society. Journal of Ethnic Foods. 2015;2:195-199
9. Malnutrition Universal Screening Tool (MUST). https://www.bapen.org.uk/pdfs/must/must_full.pdf

10. National Collaborating Centre for Acute Care, February 2006. Nutrition support in adults Oral nutrition support, enteral tube feeding and parenteral nutrition. Methods, Evidence and Guidance.
11. Nutrition Screening Tools: An Analysis of the Evidence. *Journal of Parenteral and Enteral Nutrition* 2012;36:292-298
12. O'Hara P. The management of nutrition for palliative care patients. Links to Health and Social Care.2017; 2(1):21-38
13. Ottery F. Definition of standardized nutritional assessment and intervention pathways in oncology. *Nutrition* 1996; 12(1); S15-S19.
14. Pearce CB, Duncan HD. Enteral Feeding.Nasogastric, nasojejunal, percutaneous endoscopic gastrostomy, or jejunostomy: its indications and limitations. Postgraduate Medical Journal. 2002;78:198–204
15. Rahnemai-Azar AA, Rahnemaiazar AA, Naghshizadian R, Kurtz A, Farkas DT. Percutaneous endoscopic gastrostomy: Indications, technique, complications and management. World Journal of Gastroenterology.2014 June 28; 20(24): 7739-7751
16. Shah S et al. Management of gastrointestinal symptoms in palliative care. http://rcgp-innovait.oxfordjournals.org
17. Stephen M Winter. Terminal nutrition: framing the debate for the withdrawal of nutritional support in terminally ill patients. *The American Journal of Medicine* 2000;109(9):723-726
18. van der Meij BS, Bauer JD, Isenring EA, Brown T, Davidson WL, van Bokhorst MAE, Langius JAE, van Leeuwen PAM. The effects of supplementation of n-3 polyunsaturated fatty acids on clinical outcome parameters in patients with cancer: a systematic review. *OA Epidemiology* 2013;1(1):2.

CHAPTER 20

Palliative Care Emergencies

Introduction

Palliative care emergencies are emergencies in patients with an incurable disease that may lead to death or decreased quality of life. During the palliative care phase of a patient's life, they differ from other medical emergencies and are mainly focusing on symptom control, whereas disease-oriented treatments are less important. Palliative care emergencies can occur on the physical, emotional, and existential field. They involve not only the patient but also the family and sometimes the health care professional. Palliative care emergencies that are addressed are pain, acute dyspnoea, major bleeding, acute function loss, acute anxiety, delirium, epileptic seizures, acute decompensation with aggressive behaviour of the nonprofessional caregiver, and planning for predictable emergencies.

Objective

Objective of this chapter is to gain knowledge and understanding regarding major palliative care emergencies, identifying goals of intervention and methods of managing these emergencies in the setting of palliative care.

Major emergencies in palliative care

- Superior vena cava obstruction
- Spinal cord compression

- Bleeding
- Hypercalcaemia
- Seizures

Questions to ask when considering management of emergencies in patients with advanced disease

- What is the problem?
- Can it be reversed?
- What effect will reversal of the symptom have on patient's overall condition?
- What is your medical judgment?
- What does the patient want?
- What do the carers want?
- Could active treatment maintain or improve this patient's quality of life?

Key points

- Be aware of the common emergencies in palliative care that require urgent medical treatment.
- Be aware if your patient is at risk of any emergencies.
- Know if your patient has any advance planning about what care they would like to receive in an emergency situation.
- Know how to recognize the signs and symptoms of the common emergencies.

- Now some emergency needs specific oncological management
- Know who you should call in working hours and out of hours to get help.
- In an emergency, try to remain calm, reassure the patient and those around them and communicate clearly about what's happening.

Superior Vena Cava Obstruction (SVCO)

Introduction

This is obstruction to the superior vena cava (SVC) blood flow by external compression, thrombosis or direct invasion of the SVC. It may present acutely or more insidiously as chronic dyspnoea.

Compression causes a reduction in blood flow from the head, neck and upper extremities to the heart. Low intravascular pressure in the SVC can also permit thrombus formation.

This condition may be the first presentation of malignancy or can occur in those with known malignancy. The most common cause will be carcinoma of the lung (65-80%), lymphoma (2-10%), and other cancers (3-13%). Benign causes are rare.

Assessment

Symptoms are those of venous hypertension:

- Swelling of face, neck and arms
- Breathlessness

- Visual changes
- Dizziness
- Headache – worse on stooping

Signs include:

- Conjunctival and peri-orbital oedema
- Papilloedema – late
- Dilated neck veins – non-pulsatile
- Dilated collateral veins – arms and anterior chest wall
- Oedema of hands and arms
- Stridor
- Cyanosis
- Increased respiratory rate.

Management

Treatment is dependent on the cause of the obstruction, the severity of the symptoms and the patient's prognosis. While the diagnosis of superior vena cava obstruction (SVCO) is often made on clinical grounds in patients with a history of thoracic malignancy, a chest X-ray and CT scan may confirm the diagnosis, location and extent of occlusion – mechanism of obstruction

- Sit up and ensure restricting clothing is loosened and upper arms are supported on pillows.
- Discuss with or refer urgently to oncologist, respiratory physician as appropriate.
- Arrange Systemic Anti-Cancer Therapy (SACT) and/or Radiotherapy according to the cause. E.g. For Small Cell Lung Cancer (SCLC), Lymphoma if patient's condition permits.

- Consider referral for endovascular stenting, thrombectomy, thrombolysis and anticoagulation if the patient's condition permits
- Steroids may be helpful despite the absence of evidence to support their use.

Consider dexamethasone 16mg orally or parenterally immediately and the subsequent day dexamethasone 8mg twice daily orally (second dose before 2pm if possible). Discontinue promptly if no benefit and reduce gradually in responders.

- Offer benzodiazepines, opioids, oxygen and psychological support to all patients in addition to the above measures.

Spinal Cord Compression

Introduction

Spinal Cord Compression is a major medical emergency. Its' functional outcome is dependent on the degree of neurological impairment at diagnosis. If the diagnosis is late, it can lead to permanent paralysis, sensory loss and loss of sphincter control with the poor-quality life.

Malignant spinal cord compression (MSCC) occurs when the dural sac and its contents are compressed at the level of the cord or cauda equina. This may be as a result of direct pressure, vertebral collapse or instability caused by metastatic spread or by direct extension of malignancy.

It affects about 5 to 10% of patients with cancer. Lung, breast, prostate cancers and myeloma are the commonest malignancies

involved, but MSCC should be considered in any malignancy especially with bone involvement.

Cord compression can be the initial presentation of cancer. One in 5 patients presenting with MSCC are not previously known to have malignancy.

- **Late diagnosis is common causing permanent loss of function and significant morbidity**.
- **A rapid assessment, investigation and treatment may prevent or limit irreversible neurological damage.**

Assessment

Practice Points

- Consider spinal cord compression in any patient with cancer.
- Thoracic cord compression is most common, but any part of the spine or multiple sites can be affected.
- Sites of pain and level of compression do not always correlate; X-rays and bone scans can be misleading.
- A full neurological examination should be done but may be normal initially.
- Magnetic resonance imaging (MRI) of the whole spine is the correct investigation if MSCC is suspected.

Key signs and symptoms

- New, progressively severe back pain (particularly thoracic).
- New spinal nerve root pain (burning, shooting, numbness); may radiate down anterior or posterior thigh (like sciatica), or like a band around the chest or abdomen.
- Coughing, straining or lying flat may aggravate pain.
- New difficulty walking or climbing stairs; reduced power (motor weakness),
- Sensory impairment or altered sensation in limbs.
- Bowel or bladder disturbance; Loss of sphincter control is a late sign with a poor prognosis.

Cauda equina Syndrome

Compression of lumbosacral nerve roots below the level of the cord itself results in a different clinical picture:

- New, severe root pain affecting low back, buttocks, perineum, thighs, legs
- Loss of sensation often with tingling or numbness in the saddle area
- Leg weakness, often asymmetrical
- Bladder, bowel and sexual dysfunction; occur earlier than in cord compression
- Loss of anal reflex.

Management

- Steroids should be under regular review and downward titration after radiotherapy.

- Consider gastro protection (proton pump inhibitor [PPI])
- Refer flow chart below.(Figure 1)

Figure 1: Flow chart to guide management

Patient has history of cancer and one of the following:

- New intractable, progressive pain, especially thoracic or lower limb
- New spinal nerve root pain (burning, shooting, numb)
- Any new difficulty walking (late sign)
- Reduced or altered sensation in limbs
- Bowel or bladder disturbance (late sign)
- Saddle area numbness
- Reduced anal sphincter tone.

Note: normal neurological examination does not exclude evolving spinal cord compression

Is patient fit to consider further investigation?

Patient at home or in the community	**Patient in the hospital**
Need to liaise with the regional cancer centre and transfer the patient as early as possible for further investigations	Discuss with radiology department for urgent imaging.

• **If clinical suspicion of spinal instability, manage and transport as a spinal injury.**	

If spinal cord compression is suspected and further investigation clinically appropriate, MRI should ideally be completed within 24 hours. (Discuss with radiology services – CT scanning may be more available out-of-hours)

Immediately after assessment, consider (unless contra-indicated):

- **High-dose dexamethasone,** should be started as soon as a diagnosis of cord compression is suspected:

16mg daily (usually given as 8mg twice daily – last dose ideally no later than 2pm to minimize sleep disturbance, but initial dose may need to be given as a single dose after this time).

- Gastroprotection with PPI. E.g. Omeprazole 40mg bd; iv Ranitidine 50mg bd
- Thromboprophylaxis with LMWH
- Patient should be nursed lying flat if possible.

- Pain control – see Pain Management guideline.

(If there is complete paraplegia and loss of sphincter control, radiotherapy may improve pain control but is unlikely to restore function)

If MSCC is confirmed on scan, discuss immediately with local cancer center.

If Radiotherapy appropriate:

- Transfer to regional Oncology unit for treatment and palliative care for symptom control.

If Radiotherapy not required or not possible:

- Consider palliative care in appropriate care setting

All patients with spinal cord compression will require urgent assessment and support from occupational therapy and physiotherapy, and may require social work input.

Nursing care of pressure areas, bowel and bladder are also essential.

Bleeding

Introduction

Acute haemorrhage is likely to be distressing for the patient, family and staff.

Varies from small bleeds which are fairly common, to very rarely severe life-threatening haemorrhage.

Haemorrhage (frank or occult bleeding) occurs in 10 to 20% of patients with advanced cancer. Other patients who are at risk for bleeding include

- Disorder of clotting function E.g. in liver failure,
- Disorders of platelet function E.g. in bone marrow failure in leukaemia
- Medications including anticoagulants E.g. heparin, NSAIDS E.g. naproxen, steroids E.g. dexamethasone
- Co- morbidities E.g. peptic ulcer

Assessment

- Assess whether it is severe acute bleeding, which is life threatening, or more controllable with specific measures. If the latter, discuss management with appropriate specialist.
- Also assess whether bleeding is due to local effects (such as blood vessel invasion) or to systemic effects of disease (such as disseminated intravascular coagulopathy [DIC]).
- Review the need for drugs that increase risk of bleeding, for example low molecular weight heparin, aspirin, warfarin, dexamethasone, non-steroidal anti-inflammatory drugs (NSAIDS).

Management of severe, acute bleeding

Non-pharmacological management

- Try to remain calm. Call for help. Talk to the patient and comfort them.
- Put the patient in the recovery position, if appropriate.
- If able, apply direct pressure to bleeding area; dark coloured towels are best.
- If resuscitation is appropriate, admit to hospital and manage accordingly.
- If the patient has a massive haemorrhage and is clearly dying, support and non-pharmacological interventions are more important until help arrives than trying to give sedative medication; the patient will usually lose consciousness rapidly and may be frightened especially if left alone.

Sedative medication for use in massive terminal haemorrhage

If the patient is distressed, a rapidly acting benzodiazepine is indicated. The route of administration guides the choice of drug:

- Intravenous (IV) access available: midazolam 10mg IV or diazepam 10mg IV.
- Intramuscular (IM) injection: midazolam 10mg can be given into a large muscle such as deltoid, gluteal.
- Rectal route or via a stoma: diazepam rectal solution 10mg.
- Sublingual: midazolam 10mg can be given using a parenteral preparation

Note: if the patient is already on large background doses of benzodiazepines, a larger dose may be needed. If they are frail, a smaller dose may be sufficient.

After the event

- Offer debriefing to team and family.
- Ongoing support as necessary for relatives and staff members.

Management of minor bleeding

Minor bleeding may herald a fatal bleed. Although minor, these bleeds may still be distressing to the patient and family. Following are some specific measures which can be taken to try to control these.

- Review the need for aspirin and any other drugs with antiplatelet effects such as many NSAIDs.
- Consider also if interventions, including radiotherapy, diathermy, laser, embolization, or surgery (including endoscopy, bronchoscopy, cystoscopy), are relevant.
- Assess for appropriateness and need for transfusion or other blood products.

Medication

Bleeding from skin (including fungating tumours) and mucous membranes

- Apply direct pressure if possible. This can be with gauze soaked in tranexamic acid (500mg in 5ml) or adrenaline (epinephrine) 1 in 1000.

- The tranexamic acid soaks can be left in situ with a dressing on top. Alternatively, a tranexamic acid paste (4 x 500mg tablets crushed in 60g base such as hydrophilic soft paraffin) can be applied twice daily under dressings or, in the case of oral cavity bleeding, 10ml four times daily of a 4 to 5% aqueous solution of tranexamic acid may be used as a mouth wash.
    - A 5% solution can be made by crushing and dispersing a 500mg tablet in 10ml water or diluting the contents of one 500mg/5ml ampoule to a final volume of 10ml. (If using the ampoules, the ampoule contents must be filtered before use to minimise risk of glass particles.)
- Silver nitrate sticks can be used to cauterise bleeding points.
- Surgical haemostatic sponges can be used at home by patients or families to control fast capillary bleeding.
- If bleeding not thought due to DIC, consider systemic antifibrinolytics such as tranexamic acid:
    - Initial dose of 1.5g orally followed thereafter by 1g three times daily
    - If not settling after 3 days, increase to 1.5g three times daily
    - Reduce or discontinue 1 week after bleeding stops; restart if recurs.
- Sucralfate suspension 2g in 10ml twice daily as mouth wash, or orally for oesophageal lesions or rectally for rectal lesions. A paste made of 2g (2x1g tablets crushed in 5ml aqueous jelly) can be used topically for other lesions.

Bleeding from respiratory tract

- Mortality from haemoptysis is high. Risk of asphyxiation is greater than the risk of exsanguination. Rate of bleeding affects outcome.
- Maintain the airway.

- If the bleeding site is known, lay the patient on the bleeding side to reduce effect on the other lung. Alternatively use a head down position, if possible to aid drainage of blood.
- Use oxygen and suction as required.
- Exclude or treat infection or pulmonary thromboembolism (PTE) if appropriate.
- Cough suppressant may be helpful.
- Tranexamic acid (as in section on 'Bleeding from skin and mucous membranes').
- Radiotherapy can give full control of bleeding in 85% of patients with lung bleeding.

Bleeding from urinary tract

- Exclude or treat infection.

Additional measures below may be recommended by specialists.

- Consider tranexamic acid (as in section on 'Bleeding from skin and mucous membranes') although there is a risk of clot retention until the complete cessation of bleeding.
- Bladder irrigation ± instillations with 0.9% Sodium Chloride or tranexamic acid (5g in 50ml water) can be tried once or twice daily if oral treatment is unsuccessful.

Bleeding from gastrointestinal (GI) tract (for oral or rectal bleeding see under mucous membranes)

- H2 antagonist or proton pump inhibitor.

- Tranexamic acid (as in section on 'Bleeding from skin and mucous membranes').
- Sucralfate (as in section on 'Bleeding from skin and mucous membranes') for oesophageal bleeding.
- Consider vitamin K (although paradoxically, hepatic impairment may increase risk of venous thrombosis therefore seek advice).

Bleeding due to advanced Haematological malignancy

- Platelet infusion may provide transient benefit in thrombocytopenia.
- Sensitive discussions will be required regarding the appropriateness of this treatment in marrow failure.

Practice Points

- Fear of major bleed may prevent continuing care at home.
- Advise the carer to sit or stand behind the patient when applying pressure in a severe bleed if possible as this reduces bleeding onto the carer and can limit impact of event on them. Advise them to speak to or touch the patient to reassure them they are not alone.
- All those involved with a patient who bleeds (family, carers and staff) may need support.
- Ensure bleeding is not due to dressing adherence or inappropriately vigorous cleaning of wound.

Hypercalcemia and Seizure – Refer the relevant sections

References:

1. Anwar D, Schaad N, Mazzocato C. Treatment of haemoptysis in palliative care patients. *Eur J Palliative Care*. 2003;10(4):137-9.
2. Broadley KE, Kurowska A, Dick R, Platts A, Tookman A. The role of embolization in palliative care. *Palliat Med*. 1995;9(4):331-5.
3. Dean A, Tuffin P. Fibrinolytic inhibitors for cancer-associated bleeding problems. *J Pain Symptom Manage*. 1997;13(1):20-4.
4. Doyle D, Hanks G, Cherny N, Calman K, editors. Oxford Textbook of Palliative Medicine 3rd ed. Oxford: Oxford University Press; 2004.
5. George, R., Jeba, J., Ramkumar, G., Chacko Ari, G., Leng, M. and Tharyan, P. 2008. Interventions for the treatment of metastatic extradural spinal cord compression in adults. Cochrane Database of Systematic Reviews [Online]. Available: http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD006716.pub2/abstract.
6. Levack, P., Graham, J., Collie, D., Grant, R., Kidd, J., Kunkler, I., Gibson, A., Hurman, D., Mcmillan, N., Rampling, R., Slider, L., Statham, P. and Summers, D. 2002. Don't Wait for a Sensory Level - Listen to the Symptoms: a Prospective Audit of the Delays in Diagnosis of Malignant Cord Compression. *Clinical Oncology*, 14(6), pp. 472-480.
7. Loblaw, D. A., Mitera, G., Ford, M. and Laperriere, N. J. 2012. A 2011 updated systematic review and clinical practice guideline for the management of malignant extradural spinal cord compression. *International Journal of Radiation Oncology, Biology, Physics*, 84(2), pp. 312-7.
8. Regnard C, Makin W. Management of bleeding in advanced cancer - a flow diagram. *Palliat Med*. 1992;6(1):74-8.
9. Scottish Palliative Care Guidelines
10. Stephen Falk, Marie Fallon. ABC of palliative care: Emergencies, *British Medical Journal*, 1997; 315 doi:
11. Tamagno G, Mioni R, De Carlo E, Maffei P, Rubello D, Sicolo N. Effects of a somatostatin analogue in occult gastrointestinal bleeding: a case report. *Dig Liver Dis*. 2004;36(12):843-6.

Section 5

SPECIAL PATIENT CATEGORIES

CHAPTER 21

Palliative Care in Elderly

Box 1 - Special considerations in elderly

Multi-morbidity

Combination of following non communicable diseases

- Diabetes Mellitus
- Hypertension
- Ischaemic heart disease
- Stroke
- Heart failure
- Chronic obstructive pulmonary disease,
- Parkinson disease

Geriatric syndromes

- Instability and falls
- Incontinence
- Frailty
- Delirium,
- Dementia
- Depression
- Polypharmacy

Functional impairments

- Cognitive impairment
- Impaired vision and hearing
- Loss of bladder and bowel control

Polypharmacy

- Inappropriate medications
- Irrational medications

Social issues

- Neglect and social isolation
- Poverty
- Abuse

Older people have multiple chronic diseases (multi-morbidity), displaying a wide variety of symptoms and syndromes (Box 1). A range of geriatric syndromes and symptoms occur as part of the ageing process. Social issues in elderly (Box1) pose challenges in managing them. The elderly experience functional impairment of organs, which complicate the assessment and management of symptoms. Some elderly people will not die of one specific terminal illness, but

experience combination of several factors. Their slow and dwindling decline is characterized by multiple co-morbidities and progressive functional decline resulting in increased vulnerability to minor stresses in the environment with adverse outcomes including death.

The single disease paradigm often changes to a multi-morbidity pattern in elderly. Thus they have many symptoms simultaneously and the presence of one symptom can influence the intensity of others. The disease patterns in palliative care also may show variability due to this multi-morbidity.

The use of multiple medications is common among the elderly. They are most often having more than five drugs termed as poly-pharmacy when some of them are not needed or inappropriately prescribed. The pharmacological management should consider stopping unnecessary drugs while ensuring use of essential medications to treat underlying diseases, while being cautious about adverse effects and drug interactions

Comprehensive Geriatric Assessment

The elderly patient poses many challenges to the physician as clinical presentations in the elderly can be very nonspecific. They may have multiple complex physical, psychological and social problems.

An interdisciplinary/multidisciplinary service is therefore an absolute necessity to manage these multidimensional complexities.

Box 2: Key Components of Comprehensive Geriatric Assessment (CGA)

Medical Assessment

- Problem list
- Co-morbid conditions
- Medication review
- Nutritional status/swallowing

Assessment of Function

- Basic activities of daily living
- Instrumental activities of daily living
- Vision, Hearing
- Gait & Balance

Psychological assessment

- Mental status (Cognitive testing)
- Mood (Testing for depression)

Social Assessment

- Informal support needs
- Care resource/ caregiver stress
- Financial assessment

Environmental assessment

- Home safety
- Transport

The interdisciplinary team consisting of a geriatrician/physician, nurse, physiotherapist, occupational therapist and a social worker is needed to provide a comprehensive package to the elderly.

Comprehensive Geriatric Assessment (CGA) is a multidimensional interdisciplinary diagnostic process. It focuses on assessment of a frail elderly person's medical, psychological, social problems and determines the functional status. CGA provides a coordinated & integrated plan for treatment and long term follow up.

Twenty-two randomized controlled trials which compared Comprehensive Geriatric Assessment (CGA) vs general medical care have shown that patients who had CGA are more likely to be alive and in their home after 12 months, less likely to be institutionalized after acute hospital care, less likely to suffer death or deterioration and more likely to experience improved cognition.

Integrated Care of the older person (ICOPE)

The comprehensive assessment of the elderly is an exhaustive process as all elderly patients who present to us cannot undergo CGA as it is very complex assessment. A simple way is to assess the intrinsic capacity of an older person with a tool introduced by the World Health Organization (WHO). Intrinsic capacity is defined by WHO as a combination of physical and mental capacities and functional ability of an older person as the combination and interaction of the intrinsic capacity with the environment a person inhabits.

The intrinsic capacity

The following 6 Key domains are assessed

1. Loco motor capacity
2. Vitality
3. vision
4. hearing
5. Psychological capacity - depression
6. Cognitive capacity- dementia

The assessment of the 6 key domains of an individual with this tool at primary care level will lead to a more comprehensive assessment at tertiary care level. The management of these older persons will result in improvement in the intrinsic capacity resulting in a functional ability at community level with appropriate modifications of the environment they inhabit.

ICOPE – 6 actions to improve intrinsic capacity

I. Improve musculoskeletal function, mobility and vitality

II. Maintain older adults' capacity to see and hear

III. Prevent cognitive impairment & promote psychological well-being

IV. Manage age-related conditions such as urinary incontinence

V. Prevent falls

VI. Support caregivers

Indicators for initiation of Palliative care in elderly -

Indicating terminal phase of chronic illness are

- physical decline,
- weight loss,
- multiple comorbidities, and a
- serum albumin of <2.5 g/dL.
- Dependence on assistance with most activities of daily living and a Karnofsky Performance refer the index score of less than 50%

Non-Disease Specific Indicators

- Frailty – extreme vulnerability to morbidity and mortality due to progressive decline in function and physiological reserve. Frequent falls, disability, susceptibility to acute illness and reduced ability to recover are examples of frailty.
- Functional dependence – dependence on others to perform activities of daily life
- Cognitive impairment – changes in memory, attention, thinking, language, praxis, and executive function
- Family support needs – emotional support, information and educational support unique to each patient/family and/or caregivers.

Disease Specific Markers

- Symptomatic CHF
- Dementia
- Stroke
- Cancer
- Recurrent infections
- Degenerative joint disease-causing functional impairment and chronic pain

Palliative Care for specific Diagnoses and geriatric syndromes

Falls

Assessment

Falls are multifactorial in origin, and include motor problems (gait, balance, muscle weakness), sensory impairment (vestibular, vision, peripheral neuropathy), cognitive and mood impairments, postural hypotension, medication and environmental hazards. Falls are also associated with medication such as sedative(benzodiazepines), antidepressants, antiepileptics, antipsychotics, antiparkinsonian drugs, antiarrythmics (digoxin) and urological spasmodics, antihypertensives.

Management

Multifaceted interventions should be considered, addressing the intrinsic and extrinsic factors specific to each individual include improving balance and stability, gait retraining, adjusting or ceasing psychoactive and hypotensive medicines reducing environmental hazards (Attending to loose carpets, slippery floors, low lying furniture, chairs without arm rests, good lighting), use of assistive devices, and appropriate footwear.

Frailty

Frailty is "a condition or syndrome which results from a multi-system reduction in reserve capacity to the extent that a number of physiological systems are close to or past the threshold of symptomatic clinical failure. As a consequence, the frail person is at increased risk of disability and death from minor external stresses. Frailty is believed to be a complex of interaction of several factors, including physiological alterations with ageing, comorbid disease, nutritional inadequacy, environment impacts, and genetic and lifestyle factors. It is likely that the accumulation of factors has a synergistic effect. A key feature is weight loss and sarcopenia.

Box 3: Assessment of Frailty

- A gait speed <0.8 m/s (taking >5 s to walk 4 m) or a timed-up-and-go-test (TUGT) >10 s are simple assessments
- A score of ≥3 on the PRISMA 7 questionnaire
- Polypharmacy - takes 5 or more medications which are innapropriate
- Presence of frailty syndromes such as
    - Falls (e.g. collapse, legs gave way, 'found lying on floor').
    - Immobility (e.g. sudden change in mobility, 'gone off legs' 'stuck in toilet').
    - Delirium (e.g. acute confusion, 'muddledness', sudden worsening of confusion in someone with previous dementia or known memory loss).
    - Incontinence (e.g. change in continence – new onset or worsening of urine or faecal incontinence).
    - Susceptibility to side effects of medication (e.g. confusion with codeine, hypotension with antidepressants

Management

Gold standard of management of frailty is comprehensive geriatric assessment (Box 2) and management accordingly.

Dementia

Dementia is a progressive illness for which there is no cure.

There are several key challenges in delivering effective palliative care for the person with advanced dementia. Some areas which need special consideration include difficulty in identifying a well-defined terminal phase, a more protracted duration of end stage illness over weeks to months (rather than hours to days), issues relating to communication and decision-making, assessment of pain in the cognitively impaired, and specific symptoms such as behavioral disturbances. (Sachs et al. 2004).

Families of the patient need information about:

- The patient's condition
- Future changes
- The treatment plan

There are many underlying conditions which may lead to degrees of dementia and these should be taken into account. Triggers to consider that indicate that someone is entering a later stage are:

- Unable to walk without assistance and
- Urinary and faecal incontinence, and
- No consistently meaningful conversation and
- Unable to do Activities of Daily Living (ADL)
- Barthel score <3 *(See Annex)*

Plus, any of the following:

- Weight loss
- Urinary tract Infection
- Severe pressures sores – stage three or four
- Recurrent fever
- Reduced oral intake
- Aspiration pneumonia.

It is vital that discussions with individuals living with dementia are started at an early to ensure that whilst they have mental capacity they can discuss how they would like the later stages managed.

Delirium

Delirium is a medical illness characterized by change of level of consciousness and cognition, which develops rapidly and fluctuates, occurring in the context of an underlying medical condition. Delirium is a common condition in older people, and is often unrecognized or misdiagnosed.

Assessment

Increasing age, dementia, and cognitive impairment, admission to hospital (eg for fracture or severe medical illness) are important risk factors. Being on multiple medications particularly anticholinergics, antiparkinson drugs, sedatives(benzodiazepines), withdrawal of alcohol can precipitate delirium.

Confusion assessment method (CAM)

This is done using short form, which has questions to determine each of the following

1. Acute onset and fluctuating course

2. Inattention

3.Disorganised thinking

4.Altered level of consciousness

Diagnosis of delirium requires presence of criteria 1 and 2 plus either 3 or 4. It has 94 – 100% sensitivity and 90 – 95% specificity.

Management

This has both non pharmacological and pharmacological management (Box 4) Preventive strategies include orientating approaches, managing dehydration and constipation, avoiding unnecessary catheterization, restraints, optimizing oxygen saturation, encouraging mobility, and resolving reversible causes of sensory impairments by visual and hearing aids where needed.

Box 4 : Management of delirium

Non pharmacological management

- Identify and treat the precipitating factor
- Avoid restraints
- Control pain
- Treat hypoxia
- Maintain nutrition
- Promote mobility
- Reorientation
- Promote sleep at night

Pharmacological management

Severe agitation – risk to patient or others

- Low dose haloperidol 0.25 to 0.5 mg tds
- Quetiapine 12.5 to 25 mg tds
- Risperidone 0.5 mg bd
- Olanzapine 2.5 mg bd

Special considerations in the management of pain in older person

The panel on persistent pain in older persons of the American Geriatric Society found that 25-50% of older people living in the community have major pain problems, and 45-80% nursing home residents have substantial pain that is untreated. Their pain is frequently under assessed and as a consequence poorly managed.

Age related changes in pharmacokinetics and pharmacodynamics add to the challenge of effectively managing older people's pain.

Assessment

Since elderly people have multiple health problems including arthritis and other bone, joint and back problems they often have several sources of pain. Older people also could be reluctant to report pain as they expect the symptoms are a "natural" part of ageing and do not believe that they can be alleviated. The presence of cognitive and sensory impairment among frail older people makes communication and assessment difficult. A standardized tool for assessment of pain such as a visual analogue scale (1-10) should be used where possible.

Simple nonverbal cues help in assessment of pain. Change of behavior, aggression, restlessness could signal pain. Information may be obtained from relative/care giver whether the current behavior is different from their customary behavior.

Management

Non Pharmacological methods such as therapeutic massage, distraction methods, music therapy are helpful. Elderly people are more susceptible to adverse effects and are more prone to adverse effects of medications as they are on complex drug regimens including anticoagulants. Older people are also more likely to encounter gastrointestinal bleeds with non-steroidal anti-inflammatory drugs. A time limited trial of an appropriate dose and type of analgesic should be administered with caution.

Sinhala version of Barthel Index

<u>දෛනික ක්‍රියාකාරකම්</u>

1. **ආහාර ගැනීම**
   - ☐ 0 තනිවම කළ නොහැක.
   - ☐ 5 කෙනෙකුගේ උදව් ඇතිව කළ හැක. (පිඟානට බත් බෙදා දුනහොත් හෝ අනා දුනහොත්)
   - ☐ 10 තනිවම කළ හැක.

2. **ස්නානය**
   - ☐ 0 තනිවම කළ නොහැක.
   - ☐ 5 තනිවම කළ හැක.

3. **පවිත්‍රතාවය** (දත් මැදීම, රැවුල බෑම, මුහුණ සේදීම ඇතුලුව)
   - ☐ 0 තනිවම කළ නොහැක / උදව් අවශ්‍යය.
   - ☐ 5 තනිවම කළ හැක.

4. **ඇඳුම් ඇඳීම** (බොත්තම් දැමීම, කටු ගැසීම, සපත්තු දැමීමද ඇතුලුව)
   - ☐ 0 තනිවම කළ නොහැක / උදව් අවශ්‍යය.
   - ☐ 5 තරමක් දුරට උදව් අවශ්‍යය.
   - ☐ 10 තනිවම කළ හැක.

5. **මළ පහ කිරීම**
   - ☐ 0 නිතර පාලනයක් නොමැතිව පිටවේ / නිතර වස්ති දීමට අවශ්‍යවේ.
   - ☐ 5 කලාතුරකින් පාලනයක් නොමැතිව පිටවේ.
   - ☐ 10 හොඳින් පාලනය කරගත හැක.

6. **මූත්‍රා පිට කිරීම**
   - ☐ 0 නිතර පාලනයක් නොමැතිව පිටවේ / මූත්‍රා බටයක් දමා ඇත.
   - ☐ 5 කලාතුරකින් පාලනයක් නොමැතිව පිටවේ.
   - ☐ 10 හොඳින් පාලනය කරගත හැක.

7. **වැසිකිලි භාවිතය**. (වාඩිවීම, නැගිටීම, සේදීම, ඇඳුම් ඇඳීම ඇතුලුව)
   - ☐ 0 තනිවම කළ නොහැක.
   - ☐ 5 තරමක් දුරට උපකාර අවශ්‍යවේ.
   - ☐ 10 තනිවම කරගත හැක.

8. **ඇඳෙන් පුටුවට සහ පුටුවෙන් ඇඳට මාරුවීම**.
   - ☐ 0 කළ නොහැක, තනිවම වාඩිවී සිටීමට වාරු නැත.
   - ☐ 5 කෙනෙකුගේ හෝ දෙදෙනෙකුගේ උදව් ඇතිව කළ හැක, තනිවම වාඩිවී සිටිය හැක.
   - ☐ 10 සුළු උදව්වකින් කළ හැක.
   - ☐ 15 තනිවම කළ හැක.

9. **සමතලා පොළොව මත ඇවිදීමේ හැකියාව**
   - ☐ 0 තනිවම කළ නොහැක,
   - ☐ 5 තනිවම රෝද පුටුවක් පදවාගෙන යා හැක.
   - ☐ 10 තනි පුද්ගලයකුගේ හෝ දෙදෙනෙකුගේ උදව් ඇතිව ගමන් කළ හැක.
   - ☐ 15 සැරයටියක් (හෝ වෙනත් උදව්වක්) ඇතිව හෝ නැතිව තනිවම ගමන් කළ හැක.

10. **පඩි නැගීම**
    - ☐ 0 තනිවම කළ නොහැක.
    - ☐ 5 යම් උපකාරයක් අවශ්‍යය.
    - ☐ 10 තනිවම කළ හැක.

References

1. Barer D. Inpatient comprehensive geriatric assessment improves the likelihood of living at home at 12 months. Annals of internal medicine. 2011 Dec 20;155(24):JC6-2.
2. Birch D, Draper J. A critical literature review exploring the challenges of delivering effective palliative care to older people with dementia. Journal of clinical nursing. 2008 May;17(9):1144-63.
3. Campbell AJ, Buchner DM. Unstable disability and the fluctuations of frailty. Age and ageing. 1997 Jul 1;26(4):315-8.
4. Cooper J. Diagnostic and statistical manual of mental disorders (4th edn, text revision) (DSM–IV–TR) Washington, DC: American Psychiatric Association 2000. 943 pp. £ 39.99 (hb). ISBN 0 89042 025 4. The British Journal of Psychiatry. 2001 Jul;179(1):85-.
5. Heuberger RA. The frailty syndrome: a comprehensive review. Journal of nutrition in gerontology and geriatrics. 2011 Oct 1;30(4):315-68.
6. Inouye SK, van Dyck CH, Alessi CA, Balkin S, Siegal AP, Horwitz RI. Clarifying confusion: the confusion assessment method: a new method for detection of delirium. Annals of internal medicine. 1990 Dec 15;113(12):941-8.
7. Mahoney FI, Barthel DW. Functional evaluation: The Barthel Index: a simple index of independence useful in scoring improvement in the rehabilitation of the chronically ill. Maryland state medical journal. 1965.
8. Matzo ML. Palliative Care: Prognostication and the Chronically Ill: Methods you need to know as chronic disease progresses in older adults. AJN The American Journal of Nursing. 2004 Sep 1;104(9):40-9.
9. Mor V, Laliberte L, Morris JN, Wiemann M. The Karnofsky performance status scale: an examination of its reliability and validity in a research setting. Cancer. 1984 May 1;53(9):2002-7.
10. Palliative Care for Oder people Better Practices, World Health Organization, Regional Office for Europe, 2011
11. Palliative Medicine and care of the elderly, Meera Agar and Jane Philips, Oxford Text book of Palliative Medicine.
12. Parker SG, McCue P, Phelps K, McCleod A, Arora S, Nockels K, Kennedy S, Roberts H, Conroy S. What is comprehensive geriatric assessment (CGA)? An umbrella review. Age and ageing. 2018 Jan 1;47(1):149-55.
13. Prognostic Indicator Guidance (PIG) 4th Edition Oct 2011 © The Gold Standards Framework Centre in End of Life Care CIC, Thomas.K et al
14. Wieland D, Hirth V. Comprehensive geriatric assessment. Cancer control. 2003 Nov;10(6):454-62.
15. World Health Organization. Integrated care for older people (ICOPE) implementation framework: guidance for systems and services.
16. World Health Organization. Integrated care for older people (ICOPE) implementation framework: guidance for systems and services.

CHAPTER 22

Paediatric Palliative Care

Medical professionals down the ages have been brought up, taught and trained with a tremendous emphasis on healing or curing patients although the much-quoted aphorism attributed to Hippocrates clearly states

"Cure sometimes – Treat often – Comfort always"

To change the mind set of professionals from "cure" to "care" is no easy task. In the minds of the advances and marvels of modern medicine with unimaginable progress in diagnostic and therapeutic options we still find ourselves dealing with children afflicted with life limiting conditions for which there is no reasonable hope of cure, making it most unlikely that they will live to become adults.

Lethal congenital malformations, some genetic and chromosomal disorders, heritable metabolic diseases, complex cardiac defects, neuromuscular disorders not amendable to treatment, progressive neurodegenerative disorders, extreme prematurity, hypoxic/ischaemic encephalopathy, severe cerebral palsy, renal dysplasia and agenesis leading to end stage renal diseases, fall into this category.

Some conditions found in adults as well are cancer, serious infection of brain and other systems, while trauma leading to brain and spinal cord damage also limit their future as far as years to live goes.

All these children deserve care to lead a normal life of a child interacting with family and friends, playing, singing, dancing, learning and doing everything else a normal child is expected to do.

Paediatric palliative care (PPC) is ensuring that the best possible quality of life is their right and our moral obligation. The goal in palliative care (PC) is to:-

"Add life to the child's years and not simply years to the child's life"

World Health Organisation (WHO) definition of palliative care for children with life-limiting conditions:

- It is the active total care of the child's body, mind and spirit
- It also involves extending support to the family
- It begins when illness is diagnosed and continues regardless of the child receiving disease directed treatment.
- Child's physical, psychological and social distress should be assessed and alleviated.
- Effective palliative care (PC) requires a broad inter-disciplinary approach and essentially includes the family as well as making use of available community resources.
- It can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, community health facilities or at home.

Transition to palliative care and integration

PC is still seen by most as giving medicines for pain relief to a person and this also is only at the end of life, very close to the terminal event. Palliation is seen as the last resort when everything else has failed including the notion that the physician himself or herself has fail to deliver. Expectation of a last minute miraculous healing is hoped for and physician and parents may keep on postponing introduction to PC. Many clinicians find it uncomfortable to discuss PC with parents as the term is associated with imminent death.

"anticipatory care" or "supportive care" may be more suitable terminology instead of palliative care. The children with cancer, a minority in number when considering all who need palliation, are more likely to receive PC than all the other children.

Palliation certainly includes relief from pain and other distressing symptoms and also includes efforts to enhance the quality of life and even may influence the course of the illness positively. The children who received palliation from onset of illness are found to live longer with less discomfort. Integration of PC seamlessly with disease modifying therapy is the best approach.

Team and Coordination

Professional staff involved in delivering PC are paediatricians (general and sub-specialists) oncologists, intensivists, doctors with expertise in pain management, nurses, occupational and speech therapists, play therapists, psychologists, teachers, pharmacists, counsellors and social workers.

Partnership between the child, family including siblings, grandparents, teachers, and other school staff and perhaps even work place colleagues of parents is extremely important.

One member of the team should take the role of being the coordinator who needs to be easily accessible to family at first point of contact and when moving to other places of care as well.

Advance Care Plan (ACP)

Advance care planning done initially with reviews and modification as the illness advances, is very helpful in delivering holistic care. The plan should be discussed with the child if permitted, with parents

and all the disciplines involved with the care. When developing the plans, parents' involvement is useful for them to understand the nature of the problem, management and to be prepared for future difficulties.

Family, Psycho-social support and Communication

Psycho-social support forms the foundation upon which a strong palliative care programme is built on. It is absolutely essential that the foundation is built properly, right at the beginning.

The essential aspect of the foundation is involvement with the family.

- Understanding the unique characteristics of the family.
- In the case of initial breaking of bad news, the family could get totally disrupted emotionally with disbelief, anger and sadness. Family routines get changed and financial demands increase causing a serious impact on their lives. In short, there can be loss of control over the whole situation. Coping mechanisms differ from family to family and depends on cultural and religious beliefs as well as community help. Psychological support creates and environment to empower the family to understand their strength, enable them to have control over the resources, information, decision making and forming relationships among themselves and with team mates. Empowerment of family and care givers has the potential to change the outcome positively.
- Respecting the opinion expressed by the family.
- Excellent communication, sensitive, open, honest, done to one or with the whole family, with opportunities for discussion and empowerment to expressing their own opinion is important.

- ❖ Understanding the community the family comes from, who the opinion leaders are and the impact of the community on the family, especially when deciding on a course of action.

PC support to the family should extend from the point of detection of the problem to death and bereavement. Grief reaction does not stop at the point of loss but may extend far beyond even to the adult life of siblings and friends. Parents and family experience grief with the knowledge that they are about to lose their child. Anticipatory bereavement support may be required before the actual event.

To be sensitive to all the aspects is the ultimate goal while giving the child the best possible quality of life.

In Sri Lanka, we are at the initial phase of introducing PC with the help of the Ministry of Health. The goal in PC is to have specially trained palliative care teams. However, until that goal is achieved, it is expected that the same team which provides curative treatment turns itself into the palliative care team. Current practicing paediatricians and other staff do not have the training or experience in PC for optimal symptom management and to provide anticipatory guidance. PPC concept should be included in the education of the professionals.

Professionals who care for children with life-limiting conditions are at risk of developing compassion fatigue and burnout and they also should receive support to cope with challenges encountered while providing end of life care.

References

1. De Clercq E, Rost M, Pacurari N, Elger BS, Wangmo T. Aligning guidelines and medical practice: literature review on pediatric palliative care guidelines. Palliative & supportive care. 2017 Aug;15(4):474-89.
2. Goldman A, Hain R, Liben S, editors. Oxford textbook of palliative care for children. Oxford university press; 2012 May 24.

Section 6

HOME CARE

CHAPTER 23

Home Care for the Palliative Patients

Goal of palliative care is to keep patients and loved ones comfortable and psychologically contended as much as possible, in order to improve their quality of life. Home is a place of memories and they feel familiar, relaxed and safe. Therefore, majority of patients wish to be at home with their loved ones, when they are ill, especially when they know their time is limited.

With the prevailing healthcare system, the facilities in the country are not sufficient to care for the palliating patients in institutions. Most of the health care facilities are struggling to handle the large numbers of patients presenting with acute problems. Therefore, it is impossible to keep and care for palliating patients who need long term care, in the inward setting. On the other hand, there are only a limited number of places to provide hospice care and these are far inadequate compared to the numbers who need palliative care. When palliating patients are being cared at their own home by health care team and family members, it is called 'home care for palliative patients'. Home care is the best we could provide to palliating patients at the moment, in the Sri Lankan context.

However, this should be guided and supported, to make home care more effective and a less burden to patients and families.

Advantages

- Allow the palliating patients to spend the last period of the life in their home where the majority feel safe and familiar.

- Ability to control the physical environment- noise, light, room arrangements
- Availability of 'round the clock care'- Since health care team member/s and family care givers are actively involving in caring the patients throughout the day, any changes in condition will be noticed and responded quickly
- It allows the patient to associate with the family members & friends whom the patients know and trust while receiving palliative care
- Ensure peace of mind to families and close friends since their patients are cared with the active participation of family members and health care team.
- Emotional security to patients
- Reduce cost for travelling, health institutional charges

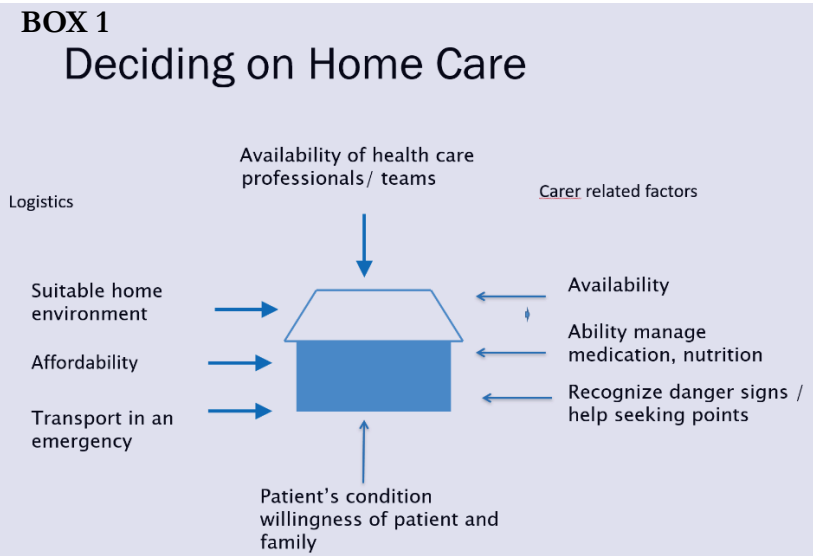
Disadvantages

- Sometimes, interference for appropriate care by family members, mainly due to emotional attachments
- Difficulties in providing confidentiality, according to patient's wishes
- Cost for health professionals and services (laboratory, procedures) if not available freely
- Minimum facilities for examination and optimal management

Evaluation for home care

Before assigning palliating patients for home-based care, it is important to perform an evaluation to ensure satisfactory care. Following are some important aspects we should assess

BOX 1



Patient's condition and willingness of the patient and family

Home-based palliative care is recommended for clinically stable patients and for patients at the terminal stage. The aspects which need to be evaluated before sending a patient home for palliation is given in the chapter on discharging home.

The appropriateness for home-based care should be communicated clearly to the patient and the family by the clinical team. Majority of people will agree to this happily, however there may be resistance due to various reasons such as fear of what to do in an emergency, non-availability of a carer, inappropriate household conditions. In these situations, the matter should be discussed with the patient and family to understand the reasons behind and appropriate guidance and support should be arranged whenever possible.

Household logistics

The home should be evaluated to see whether at least the minimum facilities necessary are available. It will be ideal if someone from the healthcare team (a nurse or a social worker) could visit the home, to assess the available facilities and to advice on modifications necessary or to advice on alternative options. For example, there are households where people share rooms/ spaces and it is not possible to arrange a room for the palliating patient. From the available space, a place should be selected to provide best possible care to the patient, which will cause least interruptions to the other family members. If the patient is not very mobile or if the toilet is situated far away from patient's room, alternative options should be sorted to provide bladder and bowel care. These may range from changing the patient's room, arranging a mobile commode, arranging bed pans, pampers or arranging a person to take the patient to the toilet. Therefore, evaluating the home environment in arranging home-based palliative care is very important for the patient, carer and for the other household members as well.

Financial situation of the family is another important aspect to consider as there will be lot of unexpected expenditure due to the needs of the patient and if the patient had been the income generator of the family, the family will have to face lot of hardships. Sometimes, caring team have to be involved in arranging financial assistance from different sources a well.

Carer related factors

Compared to an inward set up where most part of caring will be looked after by the hospital staff, in a household setting, the entire burden of caring for the patient will be on carers. Therefore, having a designated carer with proper training is very important to provide satisfactory care to patients at home. Depending on the stage of the disease of the patient, the involvement of the carer also will vary. However, with time the burden of carers will be more and more in looking after palliating patients with advancing disease.

Educating carers on managing medications, nutrition, cleanliness, and looking after catheters, NG tubes, and stomas are also very important. Informing the carers on the possible complications, identifying them, initial management and when to seek help will prevent emergency situations at home. Caring for carers to minimize the physical and psychological burden and arranging respite care to relieve them also become imperative in providing home care. All these aspects have been discussed in detail in the chapter on discharging home.

Availability of healthcare professionals

Ideally home care is provided by a multidisciplinary team (MDT) consisting of medical officers, nurses, other allied health professionals and volunteers with a training on palliative care. According to the setting, availability of above members may vary.

In the Sri Lankan context, MDTs with members from all the categories are sparse. Therefore, home care for palliating patients should be provided through the doctors available in the community settings (family practitioners/ general practitioners/ doctors attached to divisional hospitals) and the public health nursing officers. Wherever possible, the support from the other necessary

expertise should be sorted according to the specific needs of the patients.

Since the disease is progressing over the time, having an advanced care plan and a plan of management with regard to possible symptoms and expected complications given by palliative specialists will be helpful in providing a better care at community setting and will reduce unnecessary hospital admissions.

Role of primary care doctors in providing home care

A general/ family practitioner is responsible in providing comprehensive first contact care for individuals and families on a long term basis. GP/FP provides home care for the patients in the community with home visits when necessary. With the long standing doctor-patient relationship, knowledge he has about the patient's family and psychosocial background, he can take a lead role in providing home care for palliating patients.

The specialist in Family Medicine and medical officers attached to primary medical care institutions also has a good relationship with the community and are aware about the sociodemographic factors related to their community. Therefore, the doctors serving at the community level can play a pivotal role in arranging and coordinating care for palliating patients in collaboration with the family, public health nursing officers and other health care professionals.

However, the community level doctors need guidance and training in assessing patients with life limiting diseases with an emphasis on management of symptoms to make the care optimal.

Role of Public Health Nursing Officers (PHNO) in providing home care

Public Health Nursing Officers (PHNO) are attached to selected Primary Medical Care Institutions (PMCI) of the Ministry of Health. One of their tasks is provision of home-based care for palliating patients living in the designated catchment population of PMCI. They are trained on identifying physical, psychological, social & spiritual care needs of these palliative care patients. According to the need, PHNOs can arrange home visits and provide necessary care with the guidance of medical officers in the PMCI. Further, PHNOs can be utilized to train the caregivers, according to the identified needs of patients to improve the quality of life of patients and caregivers.

Challenges

To provide a quality home-based palliative care, it is mandatory to have trained and dedicated healthcare professionals serving at community level. Inputs from trained health professionals can drastically improve the care for palliating patients. At the moment, the knowledge and skills of community level health professionals in palliative care is sparse and an emphasis should be given on training in palliative care and home-based care. Having protocols for identifying and managing symptoms and clear instructions by palliative care specialists to community teams will be helpful in overcoming this challenge.

In countries with organized palliative care, the care is provided through a multidisciplinary team. Having experts in different fields in a team will reduce the burden on others. Even though having such teams is a challenge in Sri Lanka, in view of the increasing numbers needing palliative care, efforts should be made in having dedicated and trained palliative care teams.

When palliative patients are managed at home, frequent inputs from healthcare providers will be necessary, especially with fluctuating disease conditions. Home visits are time consuming and it is not easy for medical officers to assign time. Having trained PHNOs to liaise with families and medical officers, when the doctors find it difficult to do home visits will be somewhat helpful in overcoming this. However, even for the PHNOs arranging protect time for home visits will be a challenge, especially with their other work commitments and increasing number of patients needing palliative care.

In home-based palliative care, patients are being looked after by carers, mainly family members or relatives in our context. Lack of appropriate training will hinder optimal care for patients and will be distressing for the carers. With the numbers needing homebased palliative care and the diverse needs of patients, training carers is a challenge, however this will drastically improve the quality of life of patients and carers.

Lack of necessary equipment and medications is another big challenge. One example is having syringe drives to provide continuous pain relief and facilities to give oxygen at a household setting can drastically reduce unnecessary admissions at the terminal stage. There are many more instances where providing necessary medications and equipment, which could be operated at household settings could prevent hospital admissions and suffering for patients.

Family and carers will be continuously involved in care provision and decision making in home-based palliative care. This is very much helpful in most instances, however, interference with appropriate decision making may be a problem. Negotiating for withdrawing and withholding medications at the terminal stage and preparing the patient and family for impending death can be very difficult. Educating the family about the prognosis and discussing

the care plan in advance with the family will help in minimizing such problems. Communication skills training, especially on difficult communications will be useful for health care professions to manage these situations.

Even though challenging, home-based palliative care is a great option to provide better care for patients who are spending last stage of their life. Collaborative effort should be taken to strengthen home-based palliative care in Sri Lanka in order to improve the quality of life of patients and their families.

References

1. Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. Cochrane Database Syst Rev. 2013
2. Integrating palliative care and symptom relief into primary health care: a WHO guide for planners, implementers and managers. Geneva: World Health Organization; 2018
3. Kahveci K, Orhan KO, AKSAKAL H. Home-based Palliative Care. Bezmialem Science. 2020;8(1):73.
4. National Strategic Framework for Palliative Care Development in Sri Lanka 2019 – 2023, Ministry of Health, Nutrition& Indigenous Medicine; 2019.
5. Palliative Care – A Handbook for Nurses, Kerala State Resource Centre in Palliative care;2014

Section 7

END-OF-LIFE CARE

CHAPTER 24

Discharging Home and Role of the Family

Objectives

- To understand the aspects that need to be looked into before discharge
- To be able to formulate care plans for discharge
- To incorporate family and care givers in the management
- To arrange the community support services for the patient and family

Discharging a patient on palliative treatment to a community facility (**hospice**), or home is a big decision. It needs lot of planning and the planning should start from the point of admission. Involving the patient and the family/ care givers from the beginning will facilitate this process. In places where the palliative services are well established, discharge planning and the care following discharge are provided by an '**inter-disciplinary community palliative care team'**.

In the current setting, for the provision of home-based palliative care, first-contact primary care medical officer (General Practitioner or a Medical Officer in a local healthcare facility) and the other community support services need to be involved wherever possible. Community support services can be contacted with the consent of the patient and the family members through the Social Services Officer of the hospital or the Social Services Officer attached to the closest Divisional Secretariat.

Also, the Medical Officer of Health (MOH) team of the respective area can be contacted to arrange community support services. If community facilities (hospices) are available officers-in-charge of those facilities can be directly contacted. Arranging care plans with

them will facilitate better care after discharge and will prevent unnecessary further admissions.

Patients who are on palliation can be sent home for 2 reasons, (Box 1)

Box 1 : Reasons for sending palliative care patients home

1. For symptom management, after controlling the acute problems
2. For end of life care, pending death (terminal discharge)

Before discharging a patient for palliative care at home, we need to consider lot of aspects. Most importantly we must do a thorough assessment of the patient to identify the following, (Box 2)

Box 2: Factors that need to be identified before discharging a patient for palliative care at home

Disease and medication related factors:

- existing symptoms and the severity
- medications the patient is on and the possible side effects
- likely complications and the points to seek medical attention
- risk of the patient passing away while going home

Patient, family and caregiver related factors:

- patient's desire to go home
- views and concerns of family and care giver
- availability of a responsible person for providing and coordination of care
- family dynamics and relationships

Environment related factors:

- availability of first contact medical care services
- availability of other community support services

Wherever possible, a separate assessment should be done by a nursing officer to identify the aspects that need to be addressed in providing homecare. After the comprehensive assessment by the hospital palliative care team, a detailed care plan should be designed to match individual's needs. Ideally this should be written in patient's hospital records and a copy should be given to the first contact care doctor. It is better to give written instruction to family and to the social worker/ social services officer in a language and terminology they can understand.

Existing symptoms and the severity

Focused history taking and examination should be done to assess the symptoms and their severity. Patient's perceptions, ideas and expectations should be considered in this assessment.

The most common symptom among palliative patients is pain. It is important to do a proper pain assessment to identify the sites, type and the severity as there may be multiple foci for pain in the same patient. Medication should be optimized to minimise pain as much as possible and instructions on upgrading and downgrading pain medication should be given in the discharge plan. (Refer Chapter on pain)

According to the other existing symptoms and their severity, management strategies should be decided and include in the discharge plan. (Refer chapters on specific symptoms for assessment and management)

How these symptoms affect individuals, effect on activities of daily living, effect on quality of life and the effect of these symptoms on family and caregivers also should be evaluated.

Medications and possible side effects

Educate the patient and caregivers about the medications, expected duration of treatment and how to obtain refills. Explain the possible

side effects profile and pharmacological and non-pharmacological measures to overcome them. (Box 3)

Box 3: Medication management

- All the medications should be reviewed to determine the necessity.
- Essential medications should be prescribed with correct dose, frequency and duration.
- Proper instruction on administration should be given to caregivers and emphasis should be given on how to manage breakthrough symptoms and how to deviate from the routine medication.
- Contraindications and the drug interactions should be looked into.
- Inquire about the possible side effects; ensure prevention of known side effects. eg- prescribe anti-emetic and laxatives with morphine without waiting for the side effects to occur.

Likely complications and the points to seek medical attention

Complications can occur due to the disease process, due to the treatment or with the devices. Patient and the caregivers should be educated about the anticipated complications, how to identify them, initial management strategies and when to seek help.

If liaising with a local GP or a medical officer, instructions should be given on managing minor complications and about the specific referral points and the places of referral. Proper referral, back referral system can facilitate care in the hospital as well as in the community setting.

Patient, family and caregivers

In our present cultural context, we often tend to ignore the patient in decision making, especially with regard to terminal illnesses. However, our primary responsibility is to the patient and all the efforts should be taken to educate the patient about the disease process, realistic prognosis and what to expect in a sensitive manner.

Concerns and expectations of patient as well as the family and caregivers should be explored and addressed wherever possible. This will enable us to cater to patient's wishes to a certain extent and care planning will be easy.

Family and caregivers play a major role in providing palliative care. Therefore, before discharging from a hospital, someone responsible in care provision, medical officer or a senior nursing officer should have a discussion with patient and the family about the care at home.

Ideally this would be a family meeting with responsible personal from the family point of view and hospital team. Drawing a family tree to identify the members, relationships, financial status and people who can help in looking after the patient would be an immense help. This will enable us to identify the people who are likely to suffer loss and grief mostly and can start addressing it early. Getting an idea about the facilities available at home is also important in care planning.

After identifying possible caregivers, the next important thing is to train them to provide care at home. This varies from patient to patient depending on the stage of the disease and complications present nursing team can help in training the caregivers. (Box 4)

Box4

Important aspects in training of caregivers

- Training on maintaining personal hygiene and prevention of bed sores. Washing, bathing, oral care and skin care ideally should be demonstrated before discharge.
- If the patient has any tubes like NG tube, PEG, catheter, tracheostomy, a special training should be given on managing these and clear instruction on when to replace.
- Education on bladder and bowel care.
- Training on facilitating mobilization even with the help of devices like walkers or wheel chairs.
- Education on how to keep the patient comfortable, physically as well as psychologically
- Teach how to involve the patient in activities of daily living,- family activities and conversations to an extent he/she can cope. This will give them a sense of independence.
- Teach how to communicate even with who cannot respond verbally using gestures.
- Emphasize on how to identify and address emotional and spiritual needs.

Identify complications early and manage them at the community setting as much as possible. Primary caregiver and someone capable in identifying complications should be educated on the possibilities and initial management. As mentioned above, specific instructions to manage different issues to caregivers and to GP/ medical officer at the community level can prevent unnecessary admissions.

Discharging for end of life care, pending death (Terminal discharge)

Discharging home when the patient is critically ill and likely to pass away within few hours /days is defined as '**terminal discharge'**. Most patients prefer to die peacefully at home surrounded by loved ones. Whenever possible this should be encouraged.

Terminal discharge needs lot of planning in advance. Family members and caregivers should be educated about the discharge plan. Emotional preparation of the family must be done carefully as watching a dear one dying can be very traumatic. However sometimes terminal discharge may be a '**semi-emergency**' due to the unpredictability of the patient's illness.

Even at the end stage, attention should be paid to keep the patient comfortable physically, psychologically, socially & spiritually. Therefore, terminal discharge plan should be clearly communicated to the family members. Appropriate symptom control should be carefully planned for the individual needs. Religious activities may give a spiritual comfort.

Caregivers should be educated to identify when the patient enters the dying phase and symptom control at that stage to minimise the distress. Knowing the dying process will enable the family and caregivers to go through it with minimum distress. (Refer chapter on end of life care)

Caring for carers

Still in the Sri Lankan context, caregivers are mainly family members. Most of the time it will be an additional work to their daily routine. Therefore, in arranging care for a patient, especially who may go through the palliative process over a lengthy period, carer factors also should be considered.

Care givers need to look after their own health and wellbeing including personal hygiene, nutrition, coping skills, attending to follow up care of carers illnesses.

Whenever possible, members should be encouraged to take turns to prevent overburdening on one member. At least periodic breaks should be arranged to prevent burnout. If primary care giver needs a break for a rest or to attend to his /her personal need, **'respite care'** for the palliative care patient needs to be arranged temporally by another carer or at a hospice. This can be addressed before discharge, ideally in a family meeting.

Another approach to support care givers will be formation of self - help groups. Caregivers of palliative care patients can be encouraged to establish formal or informal self-help groups among care givers to share their experience with peers.

Educating the carers is another important aspect. (Box 5)

Box 5: Educating the family /caregivers

Education of family and care givers on following aspects

- Natural course of the disease process and what to expect.
- Managing the emotions during the caring process with less psychological disturbance.

Nursing team can arrange it during the hospital stay. Special attention should be given on handling the patient without hurting the carers.

Caring for a patient undergoing palliation and witnessing a loved one dying at a home setup can be very much distressing and challenging. Appropriate care planning, proper communication, guidance and support whenever necessary can minimise the problems and distress to the caregivers and enhance the quality of care for the patient. Therefore, every effort should be taken to do proper planning before discharge of a palliative care patient.

References:

1. Arias Rojas M, García-Vivar C. The transition of palliative care from the hospital to the home: a narrative review of experiences of patients and family caretakers. Investigacion y educacion en enfermeria. 2015 Dec;33(3):482-91.
2. Chur-Hansen A, Zambrano SC, Crawford GB. Furry and feathered family members—A critical review of their role in palliative care. American Journal of Hospice and Palliative Medicine®. 2014 Sep;31(6):672-7.

CHAPTER 25

Recognition of Dying and Care in the Last Days of Life

Introduction

Diagnosing dying is the first step in the management of last days of life. It is often a complex process and the predictability of death could be difficult in non-cancer patients. However, knowledge of illness trajectories and co-morbidities would help the predictability of death.

Recognition of dying

Recognition of dying is often complex. It is important to find out whether there is an expected change or an unexpected deterioration. It is further important to know why the change has occurred and whether there was any additional pathology that has taken place. Furthermore, it is important to look for reversible elements even at this dying phase. Patient's wishes needs to be considered in the managing dying phase.

Box 1: What you need to know in identifying dying phase

- Details about underlying life-limiting illness. (Knowledge, natural course
- Other comorbidities in the patient
- Presentation – whether it is related to underlying life limiting illness, exacerbation of existing comorbidities, totally unrelated problem, complications of treatment. What is the time frame of this change? Is the problem (or components thereof) reversible or not? What is the expected success rate of reversibility?
- Whether there is any unexpected frailty phase, poor symptom control, or evidence of other system failure preceding presenting illness
- What symptomatic management options are available?
- What are patient's wishes in the management under these circumstances?

Goals of care should be established by shared decision making among the patient, families/caretakers, and the medical team.

Identify potentially reversible causes

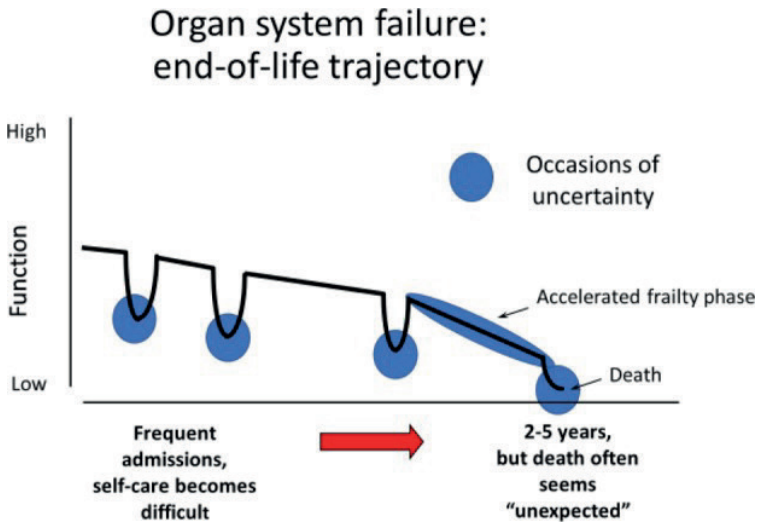
- Dehydration
- Infection
- Opioid toxicity
- Steroid withdrawal
- Acute kidney injury
- Delirium
- Hypercalcaemia
- Hypo or hyperglycaemia

How to recognize the terminal phase

Terminal phase is defined as a period of irreversible decline in functional status prior to death. Some of the common symptoms and signs seen in the terminal phase are as follows.

- Profound weakness and fatigue
- Reduced communication and social withdrawal
- Disinterest in food and drink, difficulty in swallowing medications
- Changes of breathing pattern
- Refractory delirium
- Sleeping more and drowsy for a lengthy period of the day
- Reduced urine output indicating multi system failure
- Cool, waxy looking skin

In patients with organ failures 'an accelerated frailty phase' is seen before the terminal exacerbation, even though during the preceding exacerbations too the risk of death exists.



Discussions that may need

- Discuss prognosis
- Concerns and opinion of the family,
- Information about likely course of the patient's illness and possible symptoms and emergencies.
- Individual care plan including, withdrawing and withholding futile interventions (including CPR), antibiotics, hydration and nutrition
- Degree to which the family is willing to participate in the care process and place of death.
- If it would be at home, education of the caregivers about care plan
- Preparing family for the dying process
- Assurance that the patient and family will not be abandoned.

Management

- Comfort care - Comfortable bed, pressure mattress to minimize skin breakdown, eye care, mouth care, bladder and bowel care
- Stop all unnecessary medications, investigations and monitoring
- Medicines - Assess swallowing then chose an appropriate route eg Subcutaneous

Symptom control at last days of life

Pain

- If the patient is already on oral opioids you may change to subcutaneous route (subcutaneous dose equals to half the oral dose)
- Fentanyl patches should continue.
- If patient has new pain consider increasing dose.
- For general comfort you may use 1-2 mg of morphine every 4 hourly.
- Look carefully for signs of discomfort on moving or turning
- Breakthrough analgesia can be administered hourly.

Breathlessness

- Oxygen may improve breathlessness. If needed for symptom control, give via nasal prongs.
- Flowing air from a fan may help breathlessness.

- Nursing in 45° propped up position would be more comfortable
- Consider administration of morphine. Oral or subcutaneous morphine 2.5-5 mg every 1-2 hourly or if the patient is already on opioids, 25% of 4 hourly breakthrough dose.
- Consider Anxiolytics such as midazolam 2.5-5 mg every 2-4 hourly

Terminal Restlessness

Patient may have cluster of symptoms such as fluctuating consciousness, non-purposeful motor activity, myoclonus, anxiety, and agitation which is recognized as terminal restlessness. Patient and the family members are often greatly distressed in this situation. Ward staff may find it difficult to manage this period. It is important to look for reversible elements which may be causing restlessness.

Possible reversible causes for terminal restlessness

- Urinary retention
- Constipation
- Inadequate pain control
- Medication/substance withdrawal, such as opioids, benzodiazepine, alcohol
- Metabolic factors such as hypercalcaemia, hypoglycaemia, hyponatraemia

Medication for Symptom control

- Haloperidol 2.5 -5mg SC every 8 hourly
- Midazolam 2.5 mg-5mg SC 2-4 hourly ,
- You may need a continuous infusion of 20-30mg over 24 hours in a syringe driver + midazolam SC 5mg hourly, as required or regular rectal diazepam 5-10mg 6-8 hourly
- If not responded midazolam 40-80mg over 24hours in a syringe driver + levomepromazine 12.5 mg- 25 mg , 6-12hourly, as required (stop any haloperidol)

However, try to maintain the lucidity as much as possible to enable the patient to interact with loved ones.

Respiratory secretions and death rattles

This is more distressing to the relatives than to the patient. Reassure relatives that it is not much distress to the patient. Finds hard to hear, feels like choking, drowning and it has an impact on other patients in the ward too.

- Reduce hydration - iv or s/c fluids
- Use drying subcutaneous medications prn - hyoscine hydrobromide 400mcg 2 hourly, glycopyrronium 200 mcg every 6-8hours, hyoscine butrybromide 20 mg hourly (maximum 120 mg per 24hours), atropine
- Avoid suction of secretions.

Nausea and vomiting

- If already controlled with anti-emetics change to s/c infusion
- New onset nausea and vomiting should be treated with suitable anti-emetic in a syringe driver

- haloperodol s/c 1mg 12hourly or 2 mg once a day
- levomepromazine s/c 2.5 mg 12 hourly or 5mg once a day

Hydration and nutrition

- Patient may choose to stop eating and drinking (Voluntary Stopping of Eating and Drinking- VSED) where patient takes this decision with a competent mind and physician compelled to respect this decision.
- Anorexia seems to be good at end of life since it results in ketosis, leading to peaceful state of mind and reduced pain.
- Initiating artificial nutrition and hydration does not seem to be beneficial in improving symptoms or withholding or withdrawal of such does not seem to shorten life.
- You may consider discontinuing tube feeding and IV fluids
- Explain the relatives that withholding hydration may not cause thirst. Hydration may lead to breathing difficulties and increased secretions causing further discomfort
- When oral route and tubes (NG or PEG) are not available and where you do not think of initiating tube feeding, it is reasonable to consider subcutaneous hydration.

General measures

- Keep the mouth moist with water spray, cotton swabs, ice chips
- Bladder care - may need indwelling catheter

Crisis pack

- In the event of tracheal obstruction, seizures, massive haemorrhage

- Morphine 5-10mg S/C
- Midazolam 5-10mg S/C

References

- NHS Lanakshire Guidelines
- Oxford textbook of palliative medicine – fifth edition published 2015
- NHS northern England Clinical network Palliative care and end of life care guidelines for Symptom control
- Scottish Palliative care guidelines NHS
- ABC Palliative care BMJ
- Taylor and Murray. Chron Respir Dis. 2018 Feb; 15(1): 19–25.
- https://www.jpsmjournal.com/article/S0885-3924(13)00244-3/fulltext
- Medicine; volume 43:12 December2015 www.medicinelournal.co.uk

CHAPTER 26

Ethics of End-of-Life Care

The ethics of end-of-life care (EOLC) is founded on the application of the general principles of medical ethics to the specific problems and challenges of EOLC. This chapter will begin with a brief review of the general principles of medical ethics. This will be followed by an attempt to show how these can be applied to the specific issues of EOLC.

In order to provide ethically sound care to patients at the end of life, some preliminary know-how of medical practice is necessary: clinical skills (e.g. clinical reasoning skills, communication skills), medical jurisprudence, professional conduct, and cultural sensitivity. It is beyond the scope of this chapter to explain them, but it is important to remember that practising medicine without this know-how would make ethical behaviour difficult or impossible.

Section 1: General Principles of Medical Ethics

Medical students and doctors all over the world are taught that there are four principles of medical ethics: autonomy, beneficence, non-maleficence and justice. The General Medical Council (UK) online document *Good Medical Practice* (see General Medical Council under References) provides a clear and succinct general account of how these are applied in medical practice.

These principles arose in the 1970s in a specific setting in the USA. The subsequent widespread diffusion and worldwide application of these principles, even in countries or communities which did not have the same features or demands, has been called 'principlism'.

More recently, the highly context-specific nature of these 'principles' has been widely appreciated (especially in different societies) and other principles of medical ethics have come to the fore (even in the USA). The latter include care ethics and case-based ethics, and the emergence of the value of other ethical principles such as compassion. In this brief review, however, only the four principles will be covered, since the Sri Lankan medical profession is still steeped in principlism.

Autonomy

The autonomy of a person is described as that person's capacity to form, to pursue, and to revise his/her conception of the good life. The legal definition of autonomy states that "every human being of adult years and of sound mind has a right to determine what shall be done with his body".

To exercise one's autonomy, a person must have decision-making capacity (i.e., "adult years" and "sound mind") and the means to carry out that decision (which, in medicine, requires the healthcare worker's assistance). This means that as long as the patient has decision-making capacity, a doctor must have the patient's permission to carry out any action on the patient's body, even if the doctor correctly believes that the action is beneficial to the patient. We ensure this by obtaining valid consent. However, this does not mean that the patient can demand any treatment that the doctor does not consider to be medically appropriate.

Doctors are required to presume that adult patients (i.e., in Sri Lankan law, age >18 years) have decision-making capacity unless there is grounds to suspect this (e.g., acute or chronic organic brain disease; intoxication by alcohol, substance abuse or medications; an acutely distressed person). In such situations, capacity should be formally assessed (see Dastidar & Odden, 2011). In Sri Lankan law, minors (age <18 years) do not have decision-making capacity, and

their decisions must be made by their parent or adult guardian. With regard to adults lacking capacity, in Sri Lankan law the doctor should make the decision, and that decision should be made in the patient's best interest.

Consent may be implied or expressed. Expressed consent may be expressed verbally or in writing. In general, simple and non-invasive measures (e.g., taking a history, checking blood pressure) can be carried out with implied consent. More intrusive measures (e.g., examining genitalia, drawing blood for tests, giving injections) should be carried out with verbally expressed consent. More invasive procedures (e.g., surgeries, biopsies, endoscopies, chemotherapy) require written consent. Patients must give written consent for inclusion in medical research.

In order to be valid, consent must fulfill certain requirements: disclosure of information that is necessary to make a decision and is given in a form that the patient can understand; understanding of information; voluntary decision-making; and expression of the decision made.

Other important issues that arise from autonomy include the need to respect the patient's privacy and to protect the confidentiality of information, and truth-telling.

Beneficence

Beneficence refers to the doctor's commitment to do good at all times. This goes beyond the normal civil duty of helping friends or family members. The society expects a doctor to help patients whether or not they are known to him/her and even if they are enemies or 'different' to oneself. Beneficence also presumes that the doctor is competent to help and has taken measures to ensure continued competence (such as continuing medical education and continuing professional development).

Non-maleficence

Non-maleficence refers to the doctor's commitment to avoid doing harm to the patient. This is especially important when an intervention is likely to have serious or significant side effects (e.g., surgeries, invasive procedures, chemotherapies, artificial ventilation). It may also occur in resource-poor settings, where medical care can be more likely to cause harm (e.g., nosocomial infection) or where harm is harder to avoid (e.g., when monitoring investigations are difficult to perform, patients cannot be kept in overcrowded wards to complete treatment courses). If a doctor feels that he/she is not competent enough to carry out a treatment, the doctor takes steps to obtain the necessary expertise to do it for the patient rather than potentially harm the patient by doing it incompetently him- or herself.

Justice

Justice refers to the commitment to treat like people alike – our medical decisions should be made on the basis of medical reasoning rather than non-medical reasons (such as the patient's social standing). In resource-poor settings, justice becomes an especially important issue, because we are compelled to 'ration' the available resources judiciously while various persons may pressurise us to make exceptions.

Section 2: Applying General Principles to End-of-Life Care

On Death and the Healthcare Professions

Advances in medical technology since the mid-twentieth century has resulted in the prevention of death from some previously untreatable causes (e.g., maternal death, infant and childhood death, death from acute infectious diseases, death from many forms of trauma, and now even death from ischaemic heart disease, kidney failure and some cancers). As a result, deaths due to such causes are nowadays called premature deaths.

However, there have been two unexpected, unwanted outcomes of these advances. One is the unwarranted expectation that death can be defeated, that death is due to the failure of medicine or medical care. While premature deaths could and should be prevented, death itself is not inevitable. The other unwanted outcome is the undesirable situation where technology only manages to postpone death by replacing natural life with an artificial existence that cannot be restored to normalcy (such as when a patient is kept alive with life support without the hope of a reversal to an independent existence). These two outcomes create much of the problems in EOLC today.

In addition, medical technology has given an unusual gift to humanity: it can predict death reliably in some situations where death cannot be prevented (e.g., untreatable cancers, motor neurone disease). This has given patients and families an opportunity to anticipate death and prepare for it, by making use of the remaining time in the best possible way. Commensurate with this, doctors need to develop the difficult-but-important skill of diagnosing 'the dying patient'. With this, treatment and expectations can be modified accordingly (e.g., discontinuing medications such as statins that have only long-term benefits, 'do not attempt cardiopulmonary resuscitation' / 'DNA-CPR Orders').

Another important issue is the fact that these technologies – preventing, postponing or predicting death – are often very expensive. Doctors are thus frequently called upon to face a difficult dilemma in relation to the allocation of scarce resources: the interests of one patient vs. the interests of other patients.

The Good Death

In this confusing EOLC situation, one important step is to conceptualise a 'good death', because this can serve as a guiding model for our efforts.

In western/industrialised/developed societies, where there is a lot of emphasis on the patient's autonomy, there are factors that have been identified as contributing to a good death (see Box 1).

Box 1

Attributes of a "good death" as commonly perceived by terminally ill patients and their caregivers

1. Pain and symptom management. People fear dying unattended in distress.
2. Clear decision-making. Patients feel empowered by participating in treatment decisions.
3. Preparation for death. Many patients want to know what to expect during the course of their illness. They want to plan for the events that precede and follow death.
4. Completion. Completion includes faith and spiritual experiences, life review, resolution of conflicts, spending time with family and friends, and saying goodbye.
5. Contributing to others. Many people want to contribute to the well-being of others, even as they decline and die.
6. Affirmation of the whole person. Terminally ill patients appreciate empathic caregivers who understand their current condition in the context of their lives, values, and preferences as whole and unique persons.

In western/industrialised/developed societies, strategies that have been adopted with a view to improving EOLC include provision of palliative care and hospice services, adoption of advance directives as a legal instrument, education and training of healthcare professionals, and adoption of integrated care pathways (what we call 'guidelines') for the care of the dying.

Advanced, Expensive Technology

In contrast, the common tendency in our culture is to 'do everything possible' and even to feel guilty if 'everything' was not done. In this scenario, healthcare workers may find it easier to give into two unacceptable default positions: to honour the family's wishes without exploring the patient's wishes, and to continue to provide medically futile treatment (as long as there are no practical impediments, such as lack of ability to pay).

If this approach is taken to its logical conclusion in EOLC, the patient would eventually die, the family would feel that 'everything possible was done', and the healthcare bill (including for intensive care, broad-spectrum antibiotics, invasive procedures, artificial ventilation, haemodialysis, etc.) be paid by the state or through the family's savings or sale of property. On the flip side, the patient would have silently died an undignified death that included unnecessary, invasive treatment and prolongation of suffering.

Medically Inappropriate Interventions

Medical futility is a clinical action serving no useful purpose in attaining a specific goal for a given patient. Futile treatment has been categorised into 'physiological futility' (where there is no doubt that treatment will be unsuccessful, and recovery is scientifically impossible) and 'probabilistic/quantitative futility' (where the probability of a successful outcome is extremely low but not necessarily zero, and recovery is scientifically not impossible). With physiological futility, the medical decision is clear cut. In the other

form, medical controversy is likely to occur, and a second expert opinion is invaluable.

Since the term 'futile' has been difficult to define, and has negative overtones, some have suggested the term, 'Medically inappropriate intervention' when talking with families. Furthermore, referring to the inappropriateness of an intervention highlights the importance of clarity on what is appropriate. It should be decided on each individual patient, depending on the goals of care. Goals could be changed with the progression of the illness. For example, in a patient who is diagnosed to have type 2 respiratory failure with pneumonia in the early stage of motor neurone disease where respiratory muscles function is intact, mechanical ventilation and broad-spectrum antibiotics are not considered as futile or inappropriate interventions. However, at the terminal stage of the illness, when the respiratory muscle weakness has progressed, this intervention could be determined as futile or inappropriate.

Quality of Life or Sanctity of Life?

A major reason for these differences is what people value. In much of the West, quality of life is valued over sanctity of life, while in more traditional societies the reverse may be true. But this may be a reflection of how much a society values individual autonomy too. In societies where individual autonomy is valued, the individual has greater opportunity to know his diagnosis, his dying state, and choose to avoid 'meaningless' suffering (hence prolongation of life is not a priority, for instance by artificial feeding). Where collective autonomy is valued, the individual may be 'spared the bad news' of the impending death, and his life maintained for as long as possible as a way of 'serving his best interests' even if this means that he has to suffer 'meaninglessly'.

New Legal Phenomena

Newer legal tools (such as advance directives, DNA-CPR Orders, Allow Natural Death or 'AND Orders') still do not have legal status

here. If these are used at all, it should be done cautiously and with adequate legal advice.
The current legal position regarding decision-making in the case of adult patients lacking capacity is that the doctor is required to make the decision on behalf of the patient with the patient's best interests in mind. This, however, is easier said than done. What the doctor may consider as the patient's best interests in an EOLC setting can arouse controversy, and as a result conflicts can arise with the patient's family. Besides, the doctor may also be under pressure to utilize scarce healthcare resources (especially ICU beds or haemodialysis slots) for the greatest possible benefit of a number of patients under his or her care, and not merely one patient.

Euthanasia is illegal in Sri Lanka. Unfortunately, palliative care (e.g., withholding or withdrawing 'life-support') is often mistaken for euthanasia. According to WHO declared concepts of palliative care, it neither hastens nor postpones natural death, and it affirms life and accepts death as a natural event. Clinicians must be clear about these distinctions, and must take care to explain to patients and family members the issues involved using clear, simple and effective communication.

Conclusion

These complexities require the healthcare worker to be aware of local and global trends and practices, and to be sensitive to each patient's and family's views and understandings, while working in a poor-resource setting and a background of outdated laws.

References:

1. Dastidar JG, Odden A. How do I determine if my patient has decision-making capacity? *The Hospitalist*. 2011 August, 2011(8).
2. General Medical Council. Accessed at <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/good-medical-practice> on 2021.05.15.
3. Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: observations of patients, families, and providers. *Annals of Internal Medicine* 2000; 132(10): 825-32. doi: 10.7326/0003-4819-132-10-200005160-00011. PMID: 10819707.

CHAPTER 27

Loss, Grief and Bereavement in Palliative Care

When it comes to grief and loss we are all experienced sufferers. It is part of our human birthright. There is no life without loss and therefore no life without grief
(Miriam Greenspan-Author of The Wisdom of Grief, Fear, and Despair, 2003)

Aims:

- Identify and differentiate concepts of loss, grief and bereavement in palliative care
- Recognize physical, emotional, cognitive and psycho-social aspects related to loss, grief and bereavement
- Assess, plan and provide bereavement support as necessary within palliative care framework

LOSS:
Loss is a universal aspect of life limiting illness. In palliative care settings, loss is related to 'death' of a significant person in a person's life. This is loss of a life but there may be other losses which can occur as a result of the death of the person or disease in the person.

Some of the secondary losses:

1. Physical - mobility, independence, capacity to work
2. Emotional- fear of suffering, loss of hope for living, sense of unfairness, guilt over death, loss of meaning and hope, feeling of loss of worth, loss of the social network, inability to cope, loneliness
3. Social & Economical: losing relatives or social network, job and income losses

All these losses if they become unmanageable or significant then it can have a major impact on mental health and well-being of the close relative or carers.

There are psychological responses to loss. These responses may occur not only at diagnosis, but during the course of the illness at any stage.

GRIEF:

This is the personal emotions, feelings and reactions that are expressed in various ways that can be directly related to the death of the patient. *Grieving after loss is a normal process.*

However, some grief reactions become complicated and seriously compromise health of an individual. The family, caregivers and friends in general may show different types of grief reactions due to the sadness and loss of the person they cared.

According to many palliative care guidebooks (Fallon & Hanks, 2006), grieving is a process with overlapping stages.

- **First** there is ***disbelief and shock*** about the death, timing of the death even if death was imminent. The period which this initial disbelief lasts may be shorter if death was expected within the time frame predicted due to terminal illness.
- Then this 'numbness' can be replaced ***with bouts of high and low intense distress***. Cognitive, auditory and sensory awareness about the person who died with memories, dreams and thoughts are common. Physical problems related to anxiety and sleeplessness, loss of appetite and sometimes even showing symptoms of the deceased person has been identified with some carers.
- The questioning about events related to death, finding an answer to the reasons for the death or even discussing matters of faith, religion and how it occurred is another phase where 'meaning' of the situation is constructed.
- It is common to find symptoms of depression, social withdrawal, sadness, poor concentration even one year after the death of a significant person to them.
- ***Rebuilding*** the self-identity with the loss and even move forward in different directions by taking new roles and adjusting is also part of the bereavement process. Eventually, most people will be able to remember the deceased with certain sadness but without overwhelming feelings and emotions. Coping methods are used to 'getting back' to normal routines as much as possible but for some people it may affect negatively and may use self-harming or mal-adaptive practices which needs attention from health practitioners or relatives.

Expressing grief

There are unique and different ways caregivers grieve about the death of the patient

Some different ways that the caregiver grief about

- Crying
- Being quiet
- Blaming others
- Avoiding others
- Using harmful substances
- Talking with others
- Complaining about psychosomatic issues after the death

Understanding 'grief' is a normal emotional behaviour and respecting that the way they choose to go through the grieving process is very important as well as monitoring whether the loss and grieving process is leading to self-harm of either the patient or the carer at different stages in palliative care.

.

There is no time frame for grieving process

If within the grieving process there is abnormal behaviours that are characterized by prolonged disruptions that hinder their daily routine (whether in palliative care setting or at home) such as avoidance, distancing and addiction to harmful behaviours, then primarily providing an opportunity to discuss with a skilled helper

or at secondary stage providing basic interventions of either counselling or psychiatric assessment/assistance may be required.

BREAVEMENT

This is the process that the family, carers or friends go through after the death of the patient. It includes identifying the loss, grief reactions, accepting the death and trying to continue their lives after the death of the patient as normal as possible.

In most circumstances, bereavement start with '*intense grief*' that the relative, friends and family may feel due to the death of a loved one. There is *not a specified time period or a specific way that bereavement can occur*. It depends on the religious beliefs, values and attitudes each person hold about death of a loved one and the rituals and processes that may help the grieving person to overcome this.

However, it is important that medical and support teams in palliative care settings can provide a 'preparatory help' anticipating the loss and it may reduce the intensity of the loss and help the grieving person to adjust back into their life.

Reasons for lack of re-adjustment

- **Situational:** Unexpectedness of the death, financial burdens, multiple loss situations, ethnic and cultural issues about practices after death
- **Individual**: Pre-existing health problems (mental and physical), being very close to the deceased, being widowed, being a young person, loss of a child and it's believed that ambivalent relationship with deceased person will lead to high sense distress due to unresolved issues caused by guilt
- **Environmental**: Perceived lack of social support from others increases this risk. Among elderly and younger groups, this can be due to loss of mobility and family problems that makes it difficult to overcome grief and build new bonds.
- **Interpersonal**: Ambivalent or unhealthy relationship with the deceased, significant distress experienced by carers and staff due to personality issues in the deceased patient, other interpersonal distress unrelated to deceased patient

As a medical team in a palliative care setting, it is important to **observe and monitor the relatives or the grieving persons' behaviour** at least within last few days or hours in the palliative care setting and may identify risky or self-harming display of actions or utterances (verbal and non-verbal) that requires following types of interventions:

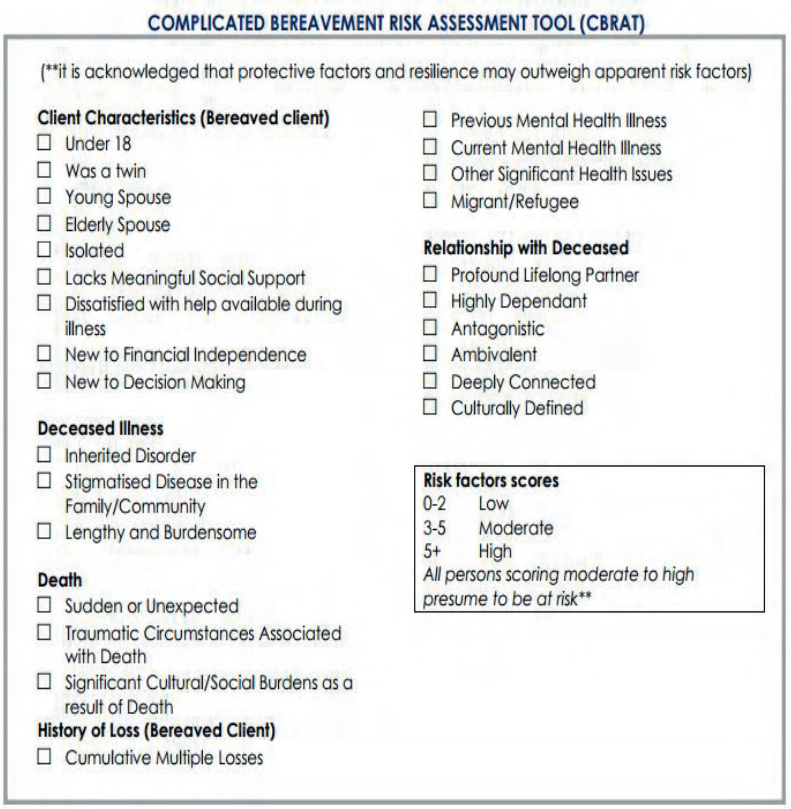
- Basic interventions (informal discussions)
- Secondary interventions (psychological counselling/psychotherapy)
- Tertiary level interventions (psychiatric assessment/treatment and assistance)

It is important to attend to vulnerable individuals of the deceased such as children, elderly and disabled and those with previous and complicated mental and physical health problems. Minority groups may also need consideration in comparison to others because of the vulnerabilities arising from their status (i.e. gender, race, ethnicity, caste, religion).

Bereavement screening tool:

Low Bereavement Risk • No or low risk of complicated grief identified by CBRAT **Management**: Many individuals deal with grief with support of family and friends.
Moderate Bereavement Risk • Minimal risk of complicated grief identified by CBRAT **Management**: Individuals in need of some additional support are identified and through peer support and trained volunteer led groups can be developed or connected to gain support through the bereavement process
High Bereavement Risk • Individuals at multiple risks of complicated grief identified by CBRAT **Management**: Need referral to specialist health professionals

Complicated Bereavement Risk Assessment Tool (CBRAT) can be used by the GP/ clinician to identify potential risks and manage needy individuals. Risk assessment can be done initially and additions can be done through subsequent visits. (Bereavement Risk Screening and Management Guidelines, 2016: GRPCC Clinical Practice Group).



COMPLICATED BEREAVEMENT RISK ASSESSMENT TOOL (CBRAT)

(**it is acknowledged that protective factors and resilience may outweigh apparent risk factors)

Client Characteristics (Bereaved client)

- ☐ Under 18
- ☐ Was a twin
- ☐ Young Spouse
- ☐ Elderly Spouse
- ☐ Isolated
- ☐ Lacks Meaningful Social Support
- ☐ Dissatisfied with help available during illness
- ☐ New to Financial Independence
- ☐ New to Decision Making

Deceased Illness

- ☐ Inherited Disorder
- ☐ Stigmatised Disease in the Family/Community
- ☐ Lengthy and Burdensome

Death

- ☐ Sudden or Unexpected
- ☐ Traumatic Circumstances Associated with Death
- ☐ Significant Cultural/Social Burdens as a result of Death

History of Loss (Bereaved Client)

- ☐ Cumulative Multiple Losses
- ☐ Previous Mental Health Illness
- ☐ Current Mental Health Illness
- ☐ Other Significant Health Issues
- ☐ Migrant/Refugee

Relationship with Deceased

- ☐ Profound Lifelong Partner
- ☐ Highly Dependant
- ☐ Antagonistic
- ☐ Ambivalent
- ☐ Deeply Connected
- ☐ Culturally Defined

Risk factors scores

0-2 Low
3-5 Moderate
5+ High
*All persons scoring moderate to high presume to be at risk***

Using your intuition and experience within the health care system may be valuable and can be utilized in such palliative care settings with further training and assistance from professionals to manage grief, loss and bereavement aspects of a patients' and their carers grief, loss and bereavement aspects of a patients' and their carers lives.

According to current research and reviews (Hudson, Hall, Boughey & Roulston, 2017)
There are principles of bereavement support and they should be delivered considering the following factors:

- **Targeted**-In a targeted manner to those individuals who would benefit greatly from specialist interventions identified through standard screening and assessment.
- **Focused**- Focusing on the existing resources and capabilities of the bereaved person so the provided support will enhance coping and resilience.
- **Continuously**- Providing the support from pre-death to post-death and as necessary when required to continue beyond this time frame.
- **To primary caregiver** -Mainly to primary caregiver but to other caregivers/family where resources are sufficient.
- **Supporting staff**- Palliative care staff should receive professional development and professional supervision

Standards for Palliative Care Services

"These standards were recommended as a minimum level of bereavement support to be provided to primary caregivers and bereaved individuals by specialist palliative care services (Hudson et al, 2017, p.5).

Standard 1: Access

Standard 2: Coordination of Bereavement Services

Standard 3: Training and Support

Standard 4: Screening and Assessment

Standard 5: Bereavement Support Strategies

Standard 6: Clinical Handover and Referral to Specialist Services

Standard 7: Community Education and Health Promotion

Standard 8: Privacy, Confidentiality and Consent

Standard 9: Integration with the Health and Support System

Standard 10: Resource Allocation

In this process some things that might help (Relf, 2006) are listed below but you may add your experiences to this and make it more culturally relevant to Sri Lankan context.

- Identifying individuals that can experience a complicated grief state
- Providing support for the death arrangements and if required an opportunity to see the body afterwards

- Providing information on practical issues (registering a death, aspects of sadness and grief, contact details on available social or psychological services)
- Opportunity to speak or meet with support groups or community services/religious groups who might help afterwards in adjustment processes

References:

1. Aranda, S & Milne, D. (2000) *Guidelines for the assessment of complicated bereavement risk in family members of people receiving palliative care.* Melbourne: Centre for Palliative Care.
2. Bereavement Risk Screening and Management Guidelines (2016) Gippsland Region Palliative Care Consortium (GRPCC) Clinical Practice Group.
3. http://inctr-palliative-care-handbook.wikidot.com/loss-grief-and-bereavement
4. http://www.grpcc.com.au/wp-content/uploads/2016/06/GRPCC-Bereavement-Screening-and-Management-Guideline-June-2016.pdf
5. Hudson, P., Hall, C., Boughey, A. & Roulston, A. (2017). Bereavement support standards and bereavement care pathway for quality palliative care. Palliative and Support Care, p.1-13. doi:10.1017/S1478951517000451
6. Marcella, J & Kelley, M.L. (2015) *Death Is Part of the Job in Long-Term Care Homes: Supporting Direct Care Staff With Their Grief and Bereavement.* Retrieved from Sage Open :http://dx.doi.org/10.1177/2158244015573912. *CC BY: Attribution*
7. Relf, M (2006). *Bereavement.* In ABC of pallitiave care (Chapter 17, pp.74-77). In M.Fallon, M & D. Doyle (Eds.). Oxford: Blackwell publishing, BMJ Books.
8. Rubel, B. (n.d.) Death, Dying, and Bereavement: Providing Compassion During a Time of Need (3rd Edition) https://www.westernschools.com/Portals/0/html/H8516/pudjeG_files/OEBPS/Text/H8516_ebooks-37.html

CHAPTER 28

Deaths at Home and Care Institutions

Deaths in palliative care settings are inevitable. Although such deaths are mostly predictable (i.e not suddenly occurring) they still contribute to the agony of already burdened families. Therefore, it is important to follow the "after-death procedures" precisely to ease the tensions.

Significance of "cause of death"

Deaths could be due to natural or unnatural causes. In modern society, it is a legal requirement that all deaths should be registered and one of the major documents needed to decide the liabilities of the deceased is the 'death certificate'. In Sri Lanka, the death registration is carried out by the Registrars of Births and Deaths appointed for administrative regions in the country[1]. A 'death certificate' is issued to the next of kin or to the closest nearest family member by the Registrar of Births and Deaths following the proper registration of the death. The main pre-requisites for registration of a death are the "cause of death" and the manner of death. The manner of death will be ascertained by an inquirer into death or by a magistrate after receiving or deciding the cause of death depending on the circumstances in relation to the death. Therefore, it is essential to realize that a primary task of any death investigation procedure is to find out, the "cause of death" for every person who dies under different circumstances.

In Sri Lankan context, there are well identified authorities who can decide on the "cause of death" of a deceased. The medical doctors are one such category. They can determine "cause of death" for most of the patients who dies in wards or units of state or private hospitals or under their care in the general practice (GP). However,

as we are aware, all human deaths are not occurring in hospitals. In such situations, where deaths occur at home or other care facilities, the deaths should be reported to the nearest 'Inquirer into Deaths' appointed for that particular region. They are also referred as 'Inquirers into Sudden Deaths' or commonly abbreviated as 'ISD's. They were previously known as 'Coroners'. The ISDs are appointed by the Minister of Justice for various jurisdictions and they are officially empowered to investigate about a death and to draw up a report of the apparent "cause of death" of a deceased in hospital bound and outside settings.

Inquest process

The information about a respective ISD appointed for a particular geographical area could be obtained from the local police station or the '*grama niladhari'* of that particular area. The death investigation carried out by an ISD is described as an "Inquest". It is a legal procedure laid out in the Code of Criminal Procedure (CCP) of Sri Lanka. (Chapter 30: Sections 369-373)[2]. In specific occasions the local magistrates could also act as Inquirers into Deaths. The whole inquest process is coordinated by the Police.

The Chapter 30 of the CCP on 'Inquests' gives a list of indications for inquests. The deaths occurring in palliative care settings are not mentioned in this list. However, it should be noted that the inquest law in Sri Lanka has not been amended since 1979 and there are many new indications (eg. deaths following interventional procedures, deaths in palliative care etc.,) that should be included in the inquest law, according to the current context. The amendments proposed to the law on "Inquests" in Sri Lanka are under consideration at present. Therefore, it should be reiterated that the best practice about deaths occurring in any kind of palliative care

settings outside the identified hospital context is to inform them to the relevant ISD directly or through Police.

If a doctor had treated a palliative care patient within the last couple of days, he/she can be called upon and following confirmation of death of the patient, that doctor may be able to provide the probable "cause of death" for the deceased. This will very much assist the ISD to complete the inquest procedure without referring to a post-mortem examination.

Correspondence with Grama Niladhari

The civil society should be aware about the remnant of death investigators who are still functioning in the Sri Lankan administrative system due to long existing lacunas in law revisions. They are 'grama niladharis' who are representing the government at grass root levels. Grama niladharis cannot hold 'inquests' into deaths according to Sri Lankan law. However, in administrative practice they are entitled to release dead bodies after a minimal documentation procedure in limited circumstances. They are mostly operational (with regard to death investigations) in semi-urban and rural areas of the country. As 'grama niladharis' are not formally trained in death investigation process, they often have difficulties in documenting cause of death according to WHO format. Although they are not permitted of carrying out death investigations in medico-legal cases, they may be called for deaths reported in palliative or terminal care settings due to logistic reasons. As a directive, deaths occurring in palliative care settings should not be informed to grama niladharis in view of getting the deceased body released for the funeral process bypassing the proper procedure route. As well-established state or private sector palliative care settings are still in infancy in Sri Lankan context, it is important to follow the appropriate directives from the beginning

so that there will be a uniform and accepted practice throughout the country in the future.

The family members of the deceased or managers of care facilities should not be feared about participating in the inquest procedure. The inquest process does not include a 'mandatory' post-mortem examination. It's only an option used at the discretion of the ISD unless specified in law. The patients undergoing palliative care or terminal care situations often have several co-morbidities and confirmed clinical diagnoses. Therefore, the requirement of subjecting such deceased to post-mortem examinations may not arise in most of the cases. The most important requirement is to provide a clear account to ISD about the circumstances that led to death of a particular patient and the 'no suspicion' declaration of next of kin/nearest relatives of the patient about the same circumstances.

It is important to submit all documents pertaining to previous medical/surgical treatment related to the deceased to ISD by the next of kin (of the deceased)/or the closest relative during the 'inquest' to ensure/facilitate the smooth flow of the process. As an inquest is a fact finding legal procedure, the ISD or the magistrate who is carrying it out has the right to request for all the medical records (BHTs, diagnosis cards, investigation results, clinic records, etc.) related to the deceased, including that are not related to the terminal illness (i.e. previous diagnosis cards, clinic records, BHTs, etc.). They also have the right to call upon any person (including medical, nursing, paramedical personnel or any caregiver/s) to provide oral evidence regarding the circumstances (including treatment) that had preceded death if deemed necessary for the inquest process. The ISD can report to Magistrate regarding a person who does not complying with his/her request.

Best practices

When a terminally ill patient or a patient undergoing palliative care meets with an accident (eg. fall, restraint etc.,) while in a health care facility, it should be informed to the relevant hospital police post / police station and should be attended by a JMO subsequently.

This should be done for every patient who is undergoing institutionalized care/ treatment and especially for a terminally ill patient or a patient undergoing palliative care because it could have a major impact on the patient's life. The caregivers of palliative and terminal care patients should be aware about the fragility of their patients and the vulnerability of those patients to even minor incidents. All possible steps should be taken at care facilities to prevent self-inflicted injuries and suicidal attempts of terminal care and palliative care patients. The feeding of patients must be done by experienced hands. The patients kept under any kind of restraint need 24-hour surveillance. The proper records should be maintained throughout for patients under monitoring.

If a terminal/palliative care patient wants to document a 'last will', his/her 'Testamentary Capacity' should be assessed preferably by a consultant forensic psychiatrist, if not by a consultant psychiatrist or a consultant JMO.

It is essential that clinicians and caregivers in terminal/palliative care settings in Sri Lanka are directed by widely accepted ethico-clinical guidelines and practices appropriate for the context during the final stages of life of the patients/persons under their care.

References

1. Births and Deaths Registration Act No. 22 of 1955
2. Code of Criminal Procedure Act No. 15 of 1979, Chapter 30

ISBN 978-624-5972-03-6

A Publication by the Sri Lanka Medical Association