Handbook of Pain Management in Palliative Care

(Public Version)

FDA
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Taiwan Food and Drug Administration
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Preface

Palliative care began in 1967 at St. Christopher's Hospice in the UK. Strategically, the WHO recommends that the promotion of palliative care as public health should encompass four main directions: policy support, education and training, practical implementation, and access to pain relief medications.

To help patients better understand methods of pain management and medication use, and to improve the function and quality of life for patients in pain, the Taiwan Food and Drug Administration commissioned Chi Mei medical center to compile this handbook. Experts from various fields such as pain management, anesthesiology, palliative medicine, family medicine, geriatrics, rehabilitation, psychiatry, preventive medicine, gastroenterology, surgery, radiology, integrative medicine, emergency medicine, pharmacy, and nursing were invited to collaborate on this project. This handbook covers various topics including an introduction to palliative care, pain assessment, care goals and strategies, commonly used pain relief methods, psychological care, treatment of specific conditions, patient self-care, and educational information for caregivers.

It is hoped that this manual will serve as a useful reference for patients receiving palliative care and experiencing pain, as well as their caregivers, to alleviate pain, improve function and quality of life, and enhance medication safety.

Director-General of Taiwan Food and Drug Administration,
Ministry of Health and Welfare Shin-Hun Juang

Editor's Note

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Chapter 1

Development of Palliative Care

1. Common misconceptions about palliative care

1.1. Palliative care is only for terminally ill patients. (Incorrect)

Fact:

Palliative care is not limited to terminally ill patients. Numerous studies show that integrating palliative care early during cancer treatment enhances patients' quality of life, reduces unnecessary emergency visits or hospitalizations, and improves satisfaction among families and healthcare teams. Additionally, some research suggests that early palliative care can potentially extend the patient's lifespan.

1.2. Hospice care is just a place to wait for death, without any treatment. (Incorrect)

Fact:

Hospice care involves proactive treatment. In fact, the treatments provided in hospice wards may sometimes be more comprehensive than in other wards. Patients at different stages of illness have varying needs, and palliative care teams provide the most suitable care tailored to these needs. Hospice care focuses on alleviating all forms of suffering. In addition to medications, a variety of complementary therapies are available. Studies have shown that patient and family satisfaction significantly increases in hospice settings.

1.3. Everyone admitted to a hospice will eventually die there. (Incorrect)

Fact:

Many patients admitted to hospice wards are discharged after their condition stabilizes and continue receiving home-based palliative care. For those with unstable conditions at home, temporary hospitalization is also an option. Residents in long-term care facilities may be admitted to hospice wards during health crises and return to their care facilities once stabilized.

1.4. Palliative care is equivalent to euthanasia. (Incorrect)

Fact:

Palliative care aims to improve patients' quality of life without hastening death. It supports a natural dying process with as little suffering as possible, emphasizing dignity and comfort during the end-of-life journey.

Table 1: Comparison of palliative care, euthanasia, and terminal cancer care in general hospitals

Palliative Care	Euthanasia	General Hospital End-of-Life Cancer Care
Emphasizes living with dignity	Emphasizes dying with dignity	Pays less attention to the dignity of life
Balances quality and quantity of life	Aims to end the patient's life	Aims to prolong the patient's life
Emphasizes familial care and connections	Focuses on the individual patient or family, with less emphasis on team care	Prioritizes medical care over family involvement
Provides palliative and supportive care	Administers lethal injections, drugs, or withdraws life-sustaining devices	Focuses solely on medical care for the patient
Offers holistic care to both patients and families, focusing on pain control, symptom relief, and spiritual support	Views the end of life as a release from suffering, dismissing the value of life extension	Focuses on aggressive treatment, often keeping terminal cancer patients in ICUs with life-support measures

1.5. All patients in hospice care use morphine for pain relief, which may lead to addiction. (Incorrect)

Fact:

While morphine use in the general population may pose a risk of addiction, the likelihood of addiction is very low when morphine is used to manage pain. Encouraging the use of morphine and other opioid medications for severe pain control is also a national policy. When prescribed and adjusted appropriately by physicians, these medications are highly safe. Furthermore, dosages are gradually reduced once symptoms are stabilized.

1.6. If morphine is used early, there will be no other options for pain relief when pain worsens later. (Incorrect)

Fact:

Morphine and other opioids have no maximum dosage limit. Research indicates that early use of pain medication when needed can make pain easier to manage in the future.

2. Definition of palliative care

In 2002, the World Health Organization (WHO) defined palliative care as an approach to care for patients and their families facing life-threatening illnesses. The goal is to improve quality of life through early assessment, prevention, and relief of suffering, addressing physical pain and other symptoms, as well as psychological, social, and spiritual issues. This definition emphasizes team-based care to meet the needs of patients and their families, providing relief for pain and distress across physical, mental, and spiritual dimensions, and assisting families during the terminal phase and the grieving process after the patient's death.

Palliative care in Taiwan emphasizes the following five aspects: Holistic Care: Includes physical, psychological, social, and spiritual care. Family-Oriented Care: Covers the needs of patients, families, and caregivers. Team-Based Care: Involves physicians, nurses, social workers, spiritual care providers, and other professionals.

Continuous Care: Encompasses all stages from the initial diagnosis of a serious illness, treatment progression, terminal care, to grief support for the family after the patient's death. Community-Based Care: Engages compassionate communities, neighbors, and groups in the care of individuals with serious illnesses.

3. New perspectives on palliative care in the 21st century

The Worldwide Hospice Palliative Care Alliance (WHPCA) has integrated the scope of palliative care services and highlighted significant changes in the traditional concept of palliative care as it has evolved into the 21st century. The focus has shifted from exclusively caring for terminal cancer patients to encompassing care for all serious progressive diseases.

	Traditional Perspective	21st Century Perspective
Concept	Focused on terminal illnesses	Focused on serious progressive diseases (not necessarily terminal)
	Prognosis limited to weeks or months	Limited life expectancy (not necessarily imminent)
	Cancer-centric	Inclusive of all progressive diseases or conditions
	Continuous decline	Disease trajectory with fluctuations and occasional exacerbations
Care Model and Setting	Exclusive choice between curative or palliative treatment	Concurrent provision of both curative and palliative care
	Specialized treatment or palliative care only	Ability to receive both types of treatment simultaneously as needed
	Palliative care based on prognosis	Palliative care based on complexity or severity
	Referral to palliative care only in late stages	Early access to palliative care in the community or various settings
	Delivered primarily in hospitals/institutions	Delivered primarily in the community
	Patients as passive recipients	Patients actively participate through advance care planning
	Fragmented care	Integrated care delivery

4. Development of palliative care in Taiwan

In 1983, the concept of palliative care in Taiwan was initiated by private organizations. Through joint efforts between civil groups and the government, three waves of development have been observed:

First Wave: The government introduced National Health Insurance (NHI) coverage for inpatient, home-based, and shared care for terminal cancer patients. It also enacted the Hospice Palliative Care Act and the Cancer Prevention Act to safeguard the dignity of terminally ill patients.

Second Wave: The palliative care movement expanded beyond cancer-specific care to include other major illnesses and various care settings.

Third Wave: Palliative care broadened to cover all age groups, from critically ill newborns to the elderly. Care settings extended to communities and long-term care facilities. The initiative also promoted compassionate communities, integrating palliative care into the healthcare system and increasing public awareness of death literacy, encouraging a positive attitude toward death.

Facing an aging population, Taiwan's palliative care movement has evolved toward diversity and comprehensiveness. Starting in June 2022, NHI expanded coverage to include four additional patient categories beyond terminal cancer and eight non-cancer terminal illnesses, with frail elderly individuals being one of them. This policy aims to provide more comprehensive care for frail elderly individuals.

Through the combined efforts of civil society and the government, Taiwan's palliative care achievements have gained both domestic and international recognition. In 2010, Taiwan ranked 14th out of 40 countries in a global quality-of-death comparison by The Economist. In 2015, the second global comparison ranked Taiwan 6th among 80 countries, with a perfect score for access to pain relief medications. By 2021, Taiwan improved further to rank 3rd among 81 countries in the third global comparison. This evaluation introduced new indicators that prioritized patient experiences, with pain management as the most important factor.

Overall, Taiwan's palliative care development has received significant international recognition. Its performance in ensuring access to and availability of pain relief medications has been commendable.

Taiwan's palliative care movement

From 1995 to 2005, the government took the lead in promoting palliative care.

The first wave of the movement

- Introduction of the concept of palliative care
- Establishment of systems and legislation to ensure a dignified end-of-life
- Formation of NGOs and professional societies
- Focus primarily on cancer
- Development of inpatient, shared care, and home-based palliative care

From 2006 to 2015

The second wave of the movement

- Palliative care for eight major non-cancer illnesses
- Advance Care Planning (ACP) / Shared Decision Making (SDM) in medical care
- Palliative care for acute and critical conditions

From 2016 to 2025

The third wave of the movement

- Palliative care for all diseases
- Palliative care for all age groups
- Early intervention in palliative care
- Community and long-term care palliative care
- New technologies and AI in palliative care
- Patient Right to Autonomy Act
- Compassionate communities/cities

5. Palliative care services in Taiwan

At present, Taiwan's palliative care services are mainly covered by the National Health Insurance (NHI), including palliative care wards, home-based palliative care services, and shared palliative care within different hospital units. With the support of NHI subsidies, the financial burden on patients is minimal.

The palliative care ward team includes physicians, nurses, social workers, psychologists, spiritual care providers, volunteers, and other members, offering holistic care to both patients and caregivers. NHI coverage differs from general hospital wards, with a fixed daily allowance that eliminates additional costs for patients. Once the patient's condition stabilizes, they can be discharged and receive home-based palliative care services.

The home is the most familiar place for patients, and through professional palliative home care nurses, patients can feel at ease staying at home. The home-based palliative care team visits regularly to address patients' problems, and patients and their families can access immediate professional support through a 24-hour support system. If necessary, arrangements can also be made for admission to palliative care wards.

The shared palliative care team provides care collaboratively with the patient's current treatment unit or assists with subsequent transfer arrangements. Research shows that patients who receive early shared palliative care experience better treatment outcomes and improved quality of life.

In an aging society, palliative care in long-term care facilities is becoming increasingly important. It allows residents with severe illnesses in long-term care institutions to be comfortably cared for in their current facilities until the end of life. Close collaboration between long-term care institutions and palliative care support organizations ensures that residents receive dignified and quality end-of-life care.

6. Conclusion

Palliative care has become an integral part of the healthcare system. It is not limited to end-of-life care but can be provided alongside active treatments, improving patients' quality of life and prognosis.

In Taiwan, palliative care is implemented through five dimensions: Holistic Care, Family-Oriented Care, Team-Based Care, Continuous Care, Community-Based Care. Taiwan's development in palliative care has received significant international recognition, particularly for its accessibility to and availability of pain relief medications. With continued government support, public awareness, and efforts from healthcare institutions, better services can be provided for patients in need of palliative care.

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Chapter 2

Introduction to Palliative Care

1. Development of palliative care in Taiwan and related regulations

The World Health Organization (WHO) defines palliative care as the provision of comprehensive physical, mental, social, and spiritual care to meet the needs of patients (including adults and children) and their families during the progression of incurable illnesses. It aims to address total suffering (or total pain), arising from the interplay of physical, mental, social, and spiritual factors, through an integrated, team-based, and person-centered approach, ultimately achieving the goals of peaceful family harmony and dignified death.

In Taiwan, palliative care services are provided by certified palliative care specialists. These services extend beyond end-of-life care for terminally ill patients to include elderly populations, chronic diseases, and conditions with limited life expectancy, emphasizing dignity and human rights throughout life until a peaceful passing.

Globally, palliative care is highly valued, yet legal provisions regarding patient groups eligible for palliative care, life-sustaining treatments (e.g., ventilators, dialysis, antibiotics for severe infections, blood transfusions), and artificial nutritional support (e.g., nasogastric tubes, gastrostomy, enterostomy, total parenteral nutrition) vary across countries. This chapter explores the status of palliative care and relevant legislation in Taiwan.

1.1. Hospice Palliative Care Act (2000)

This act, enacted in 2000 and amended three times, aims to safeguard the rights of terminally ill patients to a dignified death. Key provisions include: Individuals with legal capacity may sign a "Do-Not-Resuscitate (DNR) Consent Form," which can only be amended or revoked by the individual. For patients who are unconscious or lack legal capacity, family members may sign the DNR consent, with higher-ranked relatives having the authority to amend or revoke lower-ranked relatives' decisions (e.g., a spouse can override a child's consent). For unconscious patients without family members, the medical team may act in the patient's best interest by issuing a DNR order to facilitate a dignified death. The DNR provision ensures that patients, when facing inevitable death due to severe illness or injury, can decline CPR and other life-sustaining treatments during the dying phase, reducing futile suffering.

1.2. Patient Autonomy Act (2016)

Enacted in 2016 and effective in 2019, this act focuses on promoting patient autonomy in medical decisions and ensuring their right to informed choices and dignified death. Key provisions include: Individuals with full legal capacity can participate in advance care planning consultations and sign an Advance Directive. These consultations can be scheduled at healthcare institutions offering advance care planning services. The Advance Directive allows individuals to decide on life-sustaining treatments and artificial nutrition and hydration in five specific conditions: terminal illness, irreversible coma, permanent vegetative state, severe dementia, or conditions announced by the authorities.

1.3. Service models for palliative care

Palliative care services in Taiwan include: Inpatient hospice (hospice wards), Palliative shared care outside hospice wards, Home-based hospice care. These services are covered under the National Health Insurance (NHI) program.

1.4. Eligibility for NHI-covered palliative care

Eligible groups for NHI-covered palliative care include patients with: Cancer, motor neuron disease, cerebral degeneration, dementia, heart failure, chronic obstructive pulmonary disease (COPD), other chronic lung diseases, acute or chronic renal failure, chronic liver disease or cirrhosis. As of March 24, 2022, the NHI also includes services for: Frail elderly in terminal stages, Patients with end-stage myelodysplastic syndromes, Patients meeting conditions under Article 14, Paragraph 1, Subparagraphs 2 to 5 of the Patient Autonomy Act, Patients with rare diseases or other conditions with limited life expectancy.

1.5. Uncovered groups

Despite the WHO's definition that palliative care should cover all chronic progressive illnesses with limited life expectancy (e.g., AIDS, rheumatoid arthritis, congenital developmental anomalies, resistant chronic infections), these conditions are currently not covered under Taiwan's NHI-funded palliative care.

1.6. Scope of palliative care

Palliative care includes both pharmacological and non-pharmacological treatments to address symptoms caused by illness, providing comfort care (e.g., wound care, pain management, edema management). Psychosocial and spiritual care involves assessing and addressing patients' and families' psychological and emotional needs through counseling, helping manage various challenges, and achieving holistic, family-centered, team-based, continuous, and community-oriented care.

2. Roles and responsibilities in palliative care

The following outlines the roles and responsibilities of key members within a palliative care team:

2.1. Physicians

Assess and determine terminal illnesses. Manage disease-related symptoms. Communicate diagnoses and facilitate discussions on medical decisions, forming a continuous care plan. Provide care for patients in hospice wards, home-based hospice care, and shared palliative care settings.

2.2. Nurses

Deliver comfort-oriented nursing care. Educate family members or caregivers on proper physical care techniques. Assist in evaluating the caregiving environment and assessing family members' emotional well-being. Refer to appropriate professionals for additional support.

2.3. Social Workers

Evaluate family dynamics, human resources, and financial capacities. Facilitate mutual understanding and collaboration among family members. Provide access to various resources and assist in navigating and applying for related subsidies and services.

2.4. Psychologists

Support patients in managing emotions during their illness journey. Assess grief risk and provide emotional support for family members and caregivers. Offer recommendations for identifying and addressing symptoms such as delirium and agitation.

2.5. Dietitians

Provide chewing exercises and dietary recommendations tailored to terminally ill patients, especially those in a cachectic state. Enable terminally ill patients to enjoy flexible and safe eating in a joyful environment.

2.6. Pharmacists

Offer professional advice on medication management and end-of-life symptom relief for terminally ill patients.

2.7. Physical Therapists/Occupational Therapists/Speech Therapists

Assess and provide guidance on issues such as shortness of breath, lymphedema, functional disabilities, and swallowing difficulties. Help improve patients' functional abilities, enhance quality of life, and maintain their sense of personal dignity.

3. Common key issues in palliative care

3.1. Communication before the use of opioids (e.g., morphine)

Opioids are strongly recommended by the World Health Organization (WHO) and international guidelines as the first-line treatment for cancer pain and other severe symptoms such as intense pain or severe dyspnea in palliative care. Poorly managed pain in terminally ill patients can lead to increased mortality, comorbidity, diminished quality of life, and restricted daily activities. In Taiwan, there is a notable lack of public understanding and awareness about pain management, with significant misconceptions and even stigma surrounding opioid use. For first-time opioid users, active listening and discussions with healthcare providers can help alleviate patient and family concerns, fostering appropriate opioid use. Monitoring for potential side effects through collaboration with medical staff ensures timely interventions and allows for adjustments in prescriptions, enabling effective management of both daily and breakthrough pain.

3.2. Disclosure of illness

In clinical practice, it is not uncommon for families to withhold information about the patient's condition out of concern that they cannot cope. However, concealing the truth infringes upon the patient's right to informed consent and leaves them unable to make fully informed medical decisions. This can ultimately harm their rights and hinder their ability to make the best choices for themselves. To empower patients to make medical decisions, they must first be informed about their condition in a way they can understand, including the benefits and risks of all available medical options. Patients should be given the opportunity to reflect and decide. If disclosure proves challenging, families can seek the assistance of healthcare professionals to facilitate this process.

3.3. Preparation for death and living the remaining life

Achieving peace on physical, psychological, and spiritual levels is the key to attaining a "good death." Discussing end-of-life preparations early among family members allows patients to create the time needed to complete the "Four Tasks of Life" (expressing gratitude, love, apology, and farewell). Patients can also compile a bucket list, transform unresolved issues, and embrace personal growth. By fulfilling the final mission of life, they achieve reconciliation in their relationships with the universe, others, and themselves.

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Chapter 3

Introduction to Comprehensive Pain Management

1. Introduction

1.1. Definition of hospice and palliative care

According to Taiwan's Ministry of Health and Welfare, hospice and palliative care aims to alleviate or eliminate the physical, psychological, and spiritual suffering of terminally ill patients while enhancing their quality of life.

1.2. Definition of terminally ill patients

Terminally ill patients are those diagnosed with severe illnesses or injuries that are deemed incurable by a physician and have medical evidence indicating that the disease progression will inevitably lead to death in the near future.

1.3. Impact of pain in hospice and palliative care

Pain is a common concern for patients receiving hospice and palliative care. Its prevalence depends on the patient's condition (see Table 1 for details).

1.4. Focus of this chapter

This chapter explores pain management and care for patients receiving hospice and palliative care or terminally ill patients (hereafter referred to as "hospice patients") from a medical perspective.

Table 1: Probability of physical pain occurrence in hospice (including terminally ill) patients

The following outlines the likelihood of pain occurrence among hospice (including terminally ill) patients with different conditions:
1. Terminal cancer patients: Pain occurrence rate is approximately 70-80%. 2. Terminal heart disease patients: Pain occurrence rate is approximately 40-80%. 3. Terminal kidney disease patients: Pain occurrence rate is approximately 50%. 4. Terminal chronic obstructive pulmonary disease (COPD) patients: Pain occurrence rate is approximately 30-80%. 5. Dementia patients: Pain occurrence rate is approximately 40%. 6. Patients in intensive care units (ICU): Pain occurrence rate is approximately 50%. 7. Terminally ill patients in the last 1–3 months of life: Pain occurrence rate is approximately 40-50%. 8. Terminally ill patients in the last 4 months to 1 year of life: Pain occurrence rate is approximately 30%.

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2. Principles of pain management

2.1. The multidimensional nature of pain

Pain is a subjective experience that varies by individual and encompasses multiple dimensions:

(1) Physical dimension: Arises from bodily injury or illness.

(2) Psychological/mental dimension: Can be exacerbated by trauma, stress, or mental health conditions.

(3) Familial/social/economic dimension: Lack of support systems, such as financial stress or insufficient family support, can influence the perception of pain.

(4) Spiritual/religious/cultural dimension: Personal understanding, interpretation, and experience of pain are shaped by cultural, religious beliefs, or spiritual needs (see Figure 1 for details).

2.2. Comprehensive pain assessment and treatment

Pain management for hospice patients should adopt a comprehensive pain approach, evaluating and addressing the following dimensions: Physical, psychological, social and spiritual. Personalized treatment plans should be developed based on a multidimensional analysis.

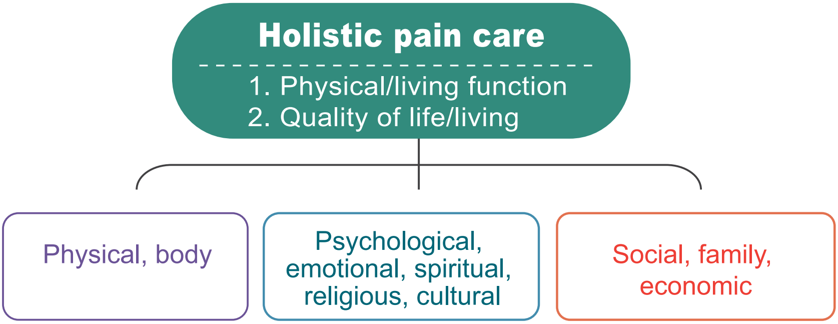
2.3. The importance of interdisciplinary collaboration

Effective pain management for hospice patients often requires the collaborative effort of:

(1) Interdisciplinary specialists: Including physicians, psychologists, social workers, and spiritual counselors.

(2) Patients, families, and caregivers: Active participation in the treatment process to jointly manage pain-related issues.

Figure 1: Holistic pain care for palliative patients



3. Goals of pain management

The core goals of pain management include:

3.1. Treating curable diseases or symptoms: Including the pain itself.

3.2. Alleviating discomfort in incurable conditions: Focus on reducing symptoms, including pain.

3.3. Restoring or partially restoring function: Helping patients regain daily routines and activities.

3.4. Enhancing quality of life: Improving emotional and psychological well-being.

4. Pain assessment

Pain assessment is critical for effective management and involves frequent and multidimensional evaluations to detect problems early and implement appropriate measures.

4.1. Regular assessments

Pain should be evaluated periodically to monitor changes in the patient's condition (see Figure 2).

4.2. Detecting loss of physical and daily functions

Pain can lead to diminished physical or daily functions. Assessments should address the following:

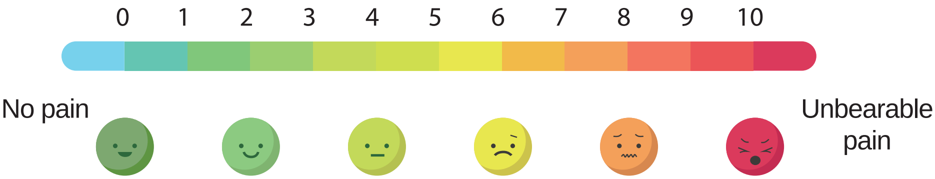
(1) Identify and treat underlying causes of pain: Determine the specific causes and provide targeted treatment.

(2) Psychological/mental factors: Assess for psychological or mental health issues, such as anxiety or depression, that may influence or exacerbate pain.

(3) Cultural factors: Evaluate whether the patient's cultural, religious, or spiritual beliefs affect their perception of pain, and tailor treatment accordingly.

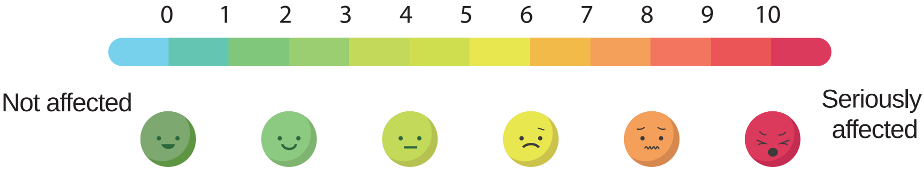
(4) Patient expectations and risk-benefit analysis: Understand the patient's expectations for pain management and carefully evaluate the potential risks and benefits to create a personalized treatment plan.

Figure 2. Assessment of pain severity (numerical scale, with relieve 10 points)



Note: The assessed items may include: at rest, during activity, at worst pain, at least pain, after medication, and after treatment; it is also possible to evaluate the overall average within a day.

Figure 3. The extent to which daily life is affected by pain (numerical scale, with 10 points)



Note: Items evaluated can include:

1. Assessment of Independence in Daily Living Activities: Activities such as bathing, dressing, toileting, mobility, and eating.
2. Assessment of Functional Disability: Tasks such as household chores, school/work participation, social activities, leisure, sexual function, and self-care.
3. Assessment of Impact on Daily Routines: Factors such as enjoyment of life, overall activity levels, sleep, and mood.

4.3. Choosing appropriate pain assessment tools

(1) General population

Use standard pain assessment tools, such as: Numeric Rating Scale (NRS), Faces Pain Scale (FPS), These tools help patients describe the intensity of their pain.

(2) Special populations

- Elderly patients: Simple and intuitive tools like the Faces Pain Scale, supplemented by observations from family members or caregivers.
- Patients with dementia: Use non-verbal assessment tools, observing facial expressions, posture, or vocal responses.
- Children: For younger children: Faces Pain Scale. For older children: Numeric Rating Scale (NRS).

- Patients with communication or cognitive impairments: Use specialized observational tools, such as PAINAD (Pain Assessment in Advanced Dementia), combined with behavioral observations.
- Critically ill patients: For patients unable to communicate, combine physiological indicators (e.g., heart rate, blood pressure) with behavioral observation tools, such as the Behavioral Pain Scale (BPS).

5. Pain management approaches

Pain management should adopt an interdisciplinary and multidisciplinary team model, integrating physical, psychological, social, and spiritual dimensions to deliver comprehensive care and support.

5.1. Physical (physiological) dimension

(1) Treatment of underlying physical conditions

Address root causes of pain, such as tumors or acute conditions, through: Surgery, chemotherapy, radiation therapy, other specialized treatments.

(2) Pharmacological pain management

Use various types of medications, including: Analgesics, antidepressants, anticonvulsants, local anesthetics.

(3) Neurological block techniques

Employ techniques such as: Temporary nerve block, nerve stimulation, nerve resection or neurolysis.

(4) Rehabilitation therapy

Incorporate diverse rehabilitation methods, such as: Assistive devices, hydrotherapy, instrumental therapy.

(5) Other therapies

Include complementary therapies, alternative medicine, and integrative medical approaches.

5.2. Psychological (mental) dimension

(1) Hospice care education

Provide patients and families/caregivers with knowledge about hospice care methods.

(2) Psychological therapy guidance

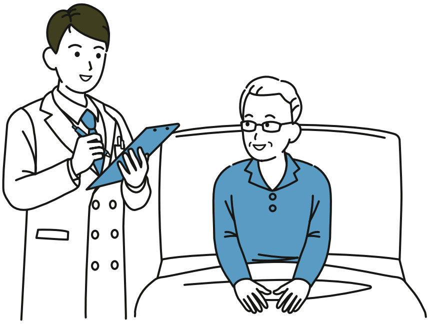
Guide patients and families in learning psychological therapy techniques to address emotional challenges.

(3) Active therapy and stress management

Encourage patients to actively participate in their treatment to reduce stress and alleviate suffering.

(4) Psychological therapy methods

Common therapies include: Cognitive Behavioral Therapy (CBT), Mindfulness-Based Stress Reduction (MBSR), Acceptance and Commitment Therapy (ACT), Relaxation training, Art and music therapy.



5.3. Social (interpersonal support) dimension

(1) Strengthening support systems

Enhance patients' familial, social, and economic support networks.

(2) Caregiver education

Train families and caregivers in providing effective support, including: Assisting with pain and medication management, offering oral care, providing emotional support, respecting patient preferences, maintaining a comfortable home environment, providing nutritional support, arranging visits from friends and family.

5.4. Spiritual dimension

(1) Support and listening

Offer empathetic support and listen patiently to patients' concerns.

(2) Respect for beliefs and values

Respect patients' beliefs and values, and understand their sources of spiritual strength.

(3) Affirmation of value

Help patients express their inner vitality, affirming their sense of purpose and abilities.

(4) Seeking physical, emotional, and spiritual comfort

(5) Guiding patients through the "four paths of life" in hospice care

Assist patients in expressing: Love, gratitude, apologies and farewells.

6. Pharmacological pain management

In 1986, the World Health Organization (WHO) introduced a three-step ladder for cancer pain management. This framework remains the cornerstone for cancer pain treatment and is widely applied in pain management for hospice patients.

6.1. Step One (mild pain)

(1) Medications: Non-opioid analgesics, such as: acetaminophen, aspirin, non-steroidal anti-inflammatory drugs (NSAIDs).

(2) Adjuvant medications: Additional drugs may be used to enhance analgesic effects when necessary.

6.2. Step Two (mild to moderate pain)

(1) Medications: Weak opioids, such as: codeine, tramadol.

(2) Adjuvant therapy: Non-opioid drugs from Step One can be combined to improve pain relief.

6.3. Step Three (moderate to severe pain)

(1) Medications: Strong opioids, such as: morphine, fentanyl.

(2) Adjuvant therapy: Non-opioid medications from Step One may be added to achieve comprehensive pain management.

Note: According to the post-2012 WHO updates, the following recommendations apply to pain management: Non-sequential Step Progression: Pain management no longer requires a step-by-step approach. Medications can be directly selected based on the severity of pain. Modified Step Two: Low-dose strong opioids can replace traditional weak opioids for more effective pain relief.

7. Pain management for terminally ill patients

Pain management is a critical aspect of care for terminally ill patients, although not all patients experience pain in their final stages of life. For those who do, timely and effective treatment is essential.

7.1. Pain is not inevitable but requires prompt attention

Not every terminal patient will experience pain during their final stages. For those who do, early assessment and intervention are necessary to alleviate suffering.

7.2. Common causes of pain in terminally ill patients

(1) Pathological fractures

Ongoing pathological fractures are a frequent source of pain and require timely treatment.

(2) Oral candidiasis

This infection can cause oral and throat pain, necessitating antifungal treatment.

(3) Urinary retention or constipation

These conditions may result in abdominal discomfort or pain and should be addressed with appropriate interventions.

(4) Pressure ulcers (bedsores)

Long-term immobility can lead to pressure ulcers, causing localized pain. Preventive care and pressure relief are crucial.

(5) Chronic pain or acute episodes

Patients may experience pre-existing chronic pain or new acute pain episodes, such as: Brain emergencies, cardiovascular emergencies, thoracic emergencies, abdominal emergencies.

7.3. Identifying and treating pain causes

(1) Identifying pain causes

Conduct a comprehensive assessment to pinpoint the specific sources of pain.

(2) Providing targeted treatment

Develop tailored treatment plans based on the identified causes, which may include: Medications, adjunct therapies, other palliative measures.

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Chapter 4

Multifaceted Pain Assessment

1. Introduction

1.1. In patients receiving palliative care or those who are terminally ill (referred to as palliative patients), their physical pain can be generally categorized into two major types:

(1) Nociceptive pain: This can be further divided into somatic pain and visceral pain.

- Somatic pain: Can be further classified into:

☆ Superficial pain sources such as pressure sores or superficial tumors or ulcers on the skin.

☆ Deep pain sources such as cancer-related bone metastasis pain, muscle spasm pain, rheumatoid or degenerative osteoarthritis.

- Visceral pain: Common causes include pancreatitis, kidney stones, gallstones, intestinal obstruction, constipation, pleural effusion, intra-abdominal cancer metastasis, pulmonary embolism, angina, bladder spasms, etc.

(2) Neuropathic pain: This can be further divided into central and peripheral neuropathic pain.

- Central neuropathic pain: Examples include post-stroke central pain, spinal cord injury or compression, brain metastasis of tumors.
- Peripheral neuropathic pain: Examples include pain from spinal nerve root compression, postherpetic neuralgia, diabetic foot pain, chemotherapy-induced peripheral neuropathy, plexus pain (e.g., cervical or brachial plexus), trigeminal neuralgia.

1.2. Common causes of physical pain in cancer patients include:

(1) Bone pain: Such as from bone cancer, bone metastasis, arthritis.

(2) Liver capsule pain: Such as from liver metastasis or other hepatobiliary pain.

(3) Headache (increased intracranial pressure): Such as from brain tumors or brain metastasis of tumors.

(4) Pancreatic pain: Such as from pancreatic tumors or pancreatitis.

(5) Abdominal smooth muscle spasm pain: Such as spasms in the bile ducts, intestines, bladder, and obstructions in the intestines or ureters.

(6) Esophageal pain: Such as from esophageal cancer or esophageal candidiasis.

(7) Rectal and lower abdominal pain: Such as from lower abdominal tumors, rectal cancer, or constipation.

(8) Pain from examinations/treatments: Such as from diagnostic procedures, surgery, radiation therapy, chemotherapy, immunotherapy, targeted therapy, cell therapy, gene therapy, etc.

1.3. In assessing pain in palliative patients, a holistic pain concept should be adopted. This means considering not only biological (physical) pain but also psychological, spiritual, cultural factors, and the lack of family, social, and economic support, which can trigger or exacerbate pain.

(1) Psychological/spiritual/religious/cultural factors:

- Psychological/psychiatric comorbidities: Anxiety disorders, depression, sleep disorders, substance use disorders (such as sedatives/hypnotics, alcohol, opioids, and drugs), and other psychiatric disorders.
- Spiritual, religious beliefs, cultural factors.

(2) Family/social/economic factors and lack of support:

- Insufficient family, economic status, medical resources, and social support: Examples include disability, living alone, elderly, poor, and difficulty accessing medical care.
- Other factors.

2. Principles of pain assessment

2.1. Allow the patient to describe their pain in their own words, and accurately understand the patient's description of the pain.

2.2. When necessary, understand the patient's pain through observation of their behavior and body language.

2.3. If the patient is unable to describe their pain, ask family members or caregivers to provide additional information.

3. Aspects of pain assessment

3.1. Assessment of pain characteristics.

3.2. Assessment of past medical history and current condition.

3.3. Assessment of functional abilities.

3.4. Assessment of psychological and social support.

3.5. Assessment of spiritual support.

3.6. Assessment of the effectiveness of pain treatment.

3.7. Assessment of pain in special populations.

3.8. Identification of situations requiring urgent intervention.

4. Assessment of pain characteristics

4.1. Common items in pain characteristics assessment:

(1) Based on the duration of the pain:

- Acute pain (pain duration less than three months).
- Chronic pain (pain duration more than three months).

(2) Based on the type of injured tissue:

- Nociceptive pain, further divided into somatic pain and visceral pain.
- Neuropathic pain.

(3) Based on the cause of the pain:

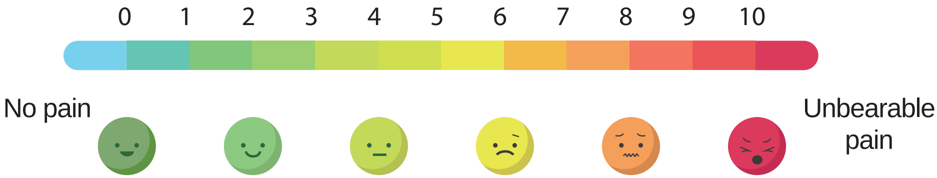
- Due to tumor invasion.
- Due to cancer treatment.
- Due to pre-existing conditions.

(4) Based on the severity of pain, using assessment scales, which can be divided into adult and pediatric scales.

Common Adult Pain Assessment Scales include the following four categories:

- Quantitative pain assessment scales (e.g., numerical rating scales as shown in Figure 1).
- Multidimensional pain assessment scales.
- Pain assessment scales for patients with cognitive impairment.
- Pain assessment scales for patients using ventilators.

Figure 1. Assessment of pain severity (numerical scale, with relieve 10 points)



Note: The assessed items may include: at rest, during activity, at worst pain, at least pain, after medication, and after treatment; it is also possible to evaluate the overall average within a day.

(5) Pain rhythm: Continuous, intermittent, or breakthrough.

(6) Assessment of breakthrough pain: Breakthrough pain can be spontaneous or triggered. The assessment includes the frequency of daily episodes, the duration of each episode, pain intensity, pain characteristics (e.g., stabbing, tearing, burning, aching), triggering factors, and alleviating factors.

4.2. In medical practice, pain characteristics can also be assessed using the English alphabet. The OPQRSTUV method can be used to examine each aspect (see Table 1 for details):

Table 1. Pain assessment (Use the English Letters OPQRSTUV to explain)

Pain Characteristic	Description
Onset	When did the pain start? How long does each episode last? How frequently does the pain occur?
Provoking / Palliating	What factors trigger the pain? What factors relieve the pain? What circumstances make the pain worse?
Quality	How does the pain feel? Examples: sharp, dull, stabbing, burning, crushing, etc.
Region / Radiation	Where is the pain located? Does the pain radiate to other areas?
Severity	Common assessment tools: 1. Numeric Rating Scale (Figure 1): Patients rate pain severity on a scale of 0–10, where 0 = no pain and 10 = unbearable pain. 2. Other scales based on patient condition: - Multidimensional pain assessment forms - Scales for cognitively impaired patients - Scales for patients on ventilators - Pediatric-specific pain scales
Treatment	What pain treatments has the patient received in the past? Examples: herbal medicine, folk remedies, massage, acupuncture, medications, or other therapies. What were the outcomes of these treatments? Did any side effects occur?

Pain Characteristic	Description
Understanding	What does the patient believe is the cause of the pain? What is the patient's main concern? What are the patient's understanding and thoughts on using controlled substances or opioid medications for pain management?
Values	Has the patient compromised with pain, such as reducing daily activities and enduring the inconvenience caused by pain? What are the patient's expectations for pain treatment? To what extent must the pain be relieved for the patient to find it acceptable? Does the patient have any special significance or interpretation of pain in their beliefs or personal values?

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5. Assessment of past medical history and current condition

5.1. Disease history: Distinguish between cancer and non-cancer, along with the treatment plan and possible future disease progression.

5.2. Other medical history: Including the treatment plan and possible future disease progression.

5.3. Medication history: Including side effects and their management.

5.4. Physical examination.

5.5. Imaging studies.

5.6. Laboratory tests.

6. Assessment of daily living functions (see Figure 2)

6.1. Assessment of independence in daily activities: Using a numerical scale (0-10), which can include bathing, dressing, toileting, mobility, and eating.

6.2. Assessment of functional disability due to pain: Using a numerical scale (0-10), which can include household chores, participation in recreational activities, social activities, employment, sexual activity, and self-care.

6.3. Other daily living function assessments: Which can include enjoyment of life, overall activity level, sleep, and mood.

Figure 2. The extent to which daily life is affected by pain (numerical scale, with 10 points)

Note: Items evaluated can include:

1. Assessment of Independence in Daily Living Activities: Activities such as bathing, dressing, toileting, mobility, and eating.
2. Assessment of Functional Disability: Tasks such as household chores, school/work participation, social activities, leisure, sexual function, and self-care.
3. Assessment of Impact on Daily Routines: Factors such as enjoyment of life, overall activity levels, sleep, and mood.

7. Assessment of psychological/mental state and family/social support

7.1. First assess the patient's communication ability and cognitive function.

7.2. Then assess the psychological stress, anxiety, and depression experienced by the patient, including their understanding of the disease, treatment, medications, and side effects, as well as emotional changes, anxiety, and depression caused by lifestyle changes.

7.3. Evaluate the patient's interpersonal/social support, including family support, economic status, and social support.

8. Assessment of spiritual support

8.1. Spiritual support can affect the patient's perception of pain.

8.2. Spiritual support includes religious beliefs and the patient's internal values and convictions.

8.3. Palliative patients often consider questions about the meaning of life, the meaning of suffering, and the value of life.

8.4. For a detailed assessment of spiritual support, see Chapter 12: Psychological, Social, and Spiritual Support.

9. Assessment and communication of pain treatment effectiveness

9.1. Inform the patient about their condition, understand their expectations, and communicate the limitations and side effects of treatment.

9.2. Make shared decisions between the healthcare provider and the patient, aiming to achieve a relatively comfortable state in terms of biological, psychological, social, and spiritual well-being post-treatment.

10. Assessment of pain in special populations (refer to extended reading 11)

10.1. Pain in neonates, infants, and preschool children can be assessed using internationally recognized pediatric assessment scales. For preschool children over three years old who can communicate effectively, pain assessment should be recorded based on the child's description.

10.2. Pain assessment in elderly individuals with intact cognitive function or mild to moderate cognitive impairment can be conducted using standard adult assessment forms.

10.3. For patients with severe cognitive impairment, delirium, or dementia, pain intensity should be judged by observing the patient's body language, facial expressions, or vocalizations.

10.4. Pain assessment and management for patients from different cultural backgrounds may vary, as the perception and interpretation of pain can differ due to religious beliefs, customs, and traditions.

10.5. For patients suspected or confirmed to have a history of substance abuse or addiction, pain assessment should involve consultation with pain management specialists and addiction treatment experts.

11. Identifying situations requiring emergency intervention

11.1. Cancer metastasis to the brain or meninges.

11.2. Cancer metastasis to the spinal cavity or epidural space.

11.3. Intestinal obstruction or perforation.

11.4. Fracture or impending fracture of major bones.

11.5. Infection, abscess, or sepsis.

11.6. Acute heart or lung failure.

12. Documentation and continuous monitoring of assessment results

12.1. Detailed assessments should be documented.

12.2. Continuous monitoring of treatment effectiveness should be conducted, and patients should be encouraged to report their status proactively.

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Chapter 5

Goals and Strategies for Pain Management

1. Introduction

1.1. The multidimensional experience of pain

Pain is a highly individualized experience, encompassing both physical sensations and emotional responses. It reflects various influences, including:

(1) Physical injury: Pain caused by illnesses or injuries.

(2) Psychological/mental trauma: Pain associated with stress, anxiety, or depression.

(3) Insufficient family/social/economic support: A lack of resources or support systems can affect how patients perceive pain.

(4) Spiritual/religious/cultural influences: Personal perceptions, interpretations, and experiences of pain may be shaped by faith, culture, or spiritual needs.

1.2. The concept of total pain

In assessing or treating pain for palliative or end-of-life patients (hereafter referred to as palliative patients), the concept of "Total Pain" should form the foundation. Comprehensive assessments and corresponding treatment plans should address the following dimensions:

(1) Physical

(2) Psychological/mental

(3) Social support

(4) Spiritual/cultural

1.3. The importance of interdisciplinary collaboration

Pain management for palliative patients often requires collective efforts from multiple parties, including:

(1) Interdisciplinary professionals: Such as physicians, nurses, psychologists, social workers, and others.

(2) Patients, families, and caregivers: Actively participating in treatment plans to create a strong support system.

2. Goals of pain management for palliative patients

Pain management for palliative patients aims to comprehensively alleviate suffering, enhance quality of life, and address their physical, psychological, social, and spiritual needs. The specific goals are as follows:

2.1. Overall goals

(1) Alleviate pain: Reduce physical discomfort experienced by the patient.

(2) Restore (or partially restore) functional capacity: Support patients in maintaining their ability to perform basic daily activities.

(3) Enhance quality of life: Focus on the overall well-being and happiness of the patient.

2.2. Specific goals

(1) Physical dimension

Relieve physical pain to help patients regain (or partially regain) basic functional abilities.

(2) Psychological dimension

Maintain emotional stability, assist patients in coping with stress, and foster inner peace and a sense of well-being.

(3) Social dimension

Strengthen interpersonal support for the patient, including care and assistance from family, friends, and the community, creating an environment filled with love and understanding.

(4) Spiritual dimension

Provide spiritual support, respect the patient's beliefs and values, and help them find inner strength and comfort.

3. Strategies for pain care in palliative patients

Pain care for palliative patients should center on holistic care, addressing physical, emotional, interpersonal, and spiritual needs. The specific strategies include:

3.1. Relieving physical pain and restoring (or partially restoring) functional abilities

(1) Arranging examinations and treatments

Conduct necessary tests and diagnostics in coordination with the hospital to identify the root cause of the pain and ensure accurate diagnosis.

(2) Providing appropriate treatments

Include treatments targeting the underlying causes of pain (e.g., illnesses or injuries) and direct pain management (e.g., analgesics or rehabilitation therapies).

(3) Restoring functional abilities

Aim to assist patients in partially or fully regaining their ability to perform daily activities through appropriate treatments.

3.2. Maintaining positive emotions and enhancing quality of life

(1) The interplay between emotions and pain

Emotions can affect pain perception, and pain can exacerbate emotional instability. Both aspects should be addressed simultaneously.

(2) Enhancing understanding for patients and caregivers

Explain the causes of pain (e.g., incurable diseases or injuries) and treatment methods to help patients and caregivers build knowledge and confidence.

(3) Psychological support and coping mechanisms

Strengthen the psychological resilience of patients and caregivers, fostering a positive mindset to face pain and illness, and promoting emotional well-being and inner peace.

3.3. Strengthening interpersonal support (family, friends, and society)

(1) Family and social support

Support, greetings, and companionship from family and friends contribute to stabilizing the patient's condition and improving emotional well-being.

(2) Seeking social resources

When necessary, leverage social resources or professional services (e.g., social workers or volunteers) to provide additional support.

3.4. Enhancing spiritual support

(1) Improving quality of life and spiritual well-being

Help patients appreciate the value of life and achieve a sense of accomplishment, enhancing their spiritual happiness.

(2) Addressing emotional farewells and spiritual anxiety

Guide patients and their families to address unresolved emotions and spiritual concerns through acts of love, gratitude, apologies, and farewells.

(3) The power of religion and faith

Utilize religion and faith to bring hope and strength to patients, helping them face the final stages of life with peace and courage.

4. Relieving physical pain and restoring (or partially restoring) functional abilities

Relieving physical pain and helping patients regain (or partially regain) functional abilities are key goals in pain management. The following are specific strategies:

4.1. Treatment of physical illnesses and tumors

(1) Address diseases or tumors causing pain, particularly acute conditions, including fractures, nerve compression, respiratory emergencies, thoracic emergencies, and brain emergencies.

(2) Treatment options include surgery, chemotherapy, radiotherapy, and other targeted therapies.

4.2. Pain management using medications

A variety of medications are used to control pain:

(1) Analgesics

(2) Antidepressants

(3) Anticonvulsants

(4) Local anesthetics

(5) Other adjuvant medications

4.3. Nerve block interventions

Specific nerve pain interventions include the following procedures:

(1) Temporary nerve block

(2) Nerve stimulation

(3) Neurolysis or nerve resection

4.4. Rehabilitation therapies

Physical therapies are employed to alleviate pain and restore function, including:

(1) Assistive devices, such as walkers and braces.

(2) Hydrotherapy, such as soaking in hot springs.

(3) Instrumental therapies, such as ultrasound or electrotherapy.

4.5. Other therapies

Incorporating various non-traditional or complementary therapies, such as:

(1) Complementary therapies, like massage and acupuncture.

(2) Alternative therapies, such as aromatherapy and herbal treatments.

(3) Integrative medicine, combining modern and traditional treatments for holistic care.

4.6. Self-directed physical training

Patients can choose appropriate daily activities and exercises based on their physical condition, including:

(1) Simple stretching exercises

(2) Practices like tai chi and yoga

(3) Moderate exercise to enhance physical strength, improve functionality, and alleviate pain.

5. Maintaining positive emotions and enhancing quality of life

In palliative care, maintaining positive emotions and enhancing quality of life are vital goals. The following are specific measures:

5.1. Patient self-care

(1) Physical care: Maintain physical health and comfort.

(2) Create a comfortable environment: Foster a relaxing home atmosphere.

(3) Pain management: Regularly address pain to improve quality of life.

(4) Breathing exercises: Relieve stress and improve respiratory function.

(5) Massage and light exercise: Promote blood circulation and alleviate discomfort.

(6) Music and art therapy: Help relax and enhance a sense of well-being.

5.2. Maintaining good sleep quality

(1) Regular routines: Establish a stable sleep schedule.

(2) Comfortable sleep environment: Ensure a quiet and temperature-appropriate bedroom.

(3) Avoid stimulants: Refrain from coffee, alcohol, or smoking before bed.

(4) Pre-sleep relaxation: Engage in calming activities like deep breathing or meditation.

(5) Assistive tools: Use devices like breathing aids if needed to resolve sleep issues (e.g., snoring).

5.3. Stress relief and resilience building

(1) Deep breathing and meditation: Reduce anxiety and stress.

(2) Psychological support: Seek help from mental health professionals or loved ones.

(3) Cultivate hobbies: Engage in enjoyable activities to enrich life.

(4) Art and music: Use creative outlets to soothe emotions.

(5) Family activities: Strengthen emotional bonds through family gatherings.

(6) Conversations with friends: Share feelings and gain support.

5.4. Utilizing psychotherapy

(1) Cognitive behavioral therapy (CBT): Adjust cognitive and emotional responses to pain.

(2) Mindfulness meditation: Focus on the present to reduce negative emotions.

(3) Relaxation therapy: Achieve physical and mental relaxation.

(4) Music therapy: Use music to alleviate stress and improve mood.

(5) Positive reframing: Adopt an optimistic attitude to overcome challenges and enhance happiness.

5.5. Balanced and healthy diet

(1) Taste preferences: Adjust meals to make eating enjoyable.

(2) Small, frequent meals: Avoid large portions to reduce digestive burden.

(3) Healthy food choices: Include vegetables, fruits, nuts, and fresh fish and meat.

(4) Nutritional supplements: Use supplements if necessary to maintain balanced nutrition.

5.6. Light physical activities

(1) Mood enhancement: Light exercises improve emotional well-being.

(2) Suitable activities: Engage in activities like post-meal walks to maintain muscle strength.

(3) Joint mobility: Perform moderate joint exercises to maintain flexibility.

(4) Physician-recommended activities: Tailor exercise intensity and methods based on physical condition.

6. Strengthening interpersonal support (family, friends, and society) to maintain positive emotions and enhance quality of life

Interpersonal support is a crucial factor in improving the quality of life for patients. Care and assistance from family, friends, and society can effectively help patients alleviate physical and mental burdens while improving their emotional well-being. The following are specific strategies:

6.1. Maintaining a positive mindset

(1) Practice gratitude: Learn to appreciate the good things in life, fostering inner peace and enrichment.

(2) Cultivate contentment: Cherish the present and find joy in life's small blessings.

(3) Strengthen interpersonal connections: Actively reach out to family and friends, reinforcing mutual relationships and support networks.

6.2. Seeking assistance

(1) Support from family and friends

The care and companionship of family and friends play a significant role in stabilizing the patient's emotions and supporting pain management.

(2) Enhancing understanding among family members and caregivers

Healthcare professionals can help by explaining the patient's physical and emotional condition, enabling family members and caregivers to understand the patient's pain and needs, thus providing more effective support.

(3) Utilizing social resources

When necessary, seek assistance from social resources (e.g., social workers or volunteer groups) to share caregiving responsibilities and enhance the patient's support system.

7. Enhancing spiritual support

Spiritual support has a profound impact on a patient's emotional balance and quality of life. The following are practical methods for implementing spiritual care:

7.1. Participation in spiritual activities

(1) Activities aligned with beliefs and values: Engage in prayer, meditation, or religious ceremonies to help patients find inner peace and strength.

(2) Sharing memories and gratitude: Exchange cherished memories and express gratitude with family and friends, deepening emotional connections.

7.2. Practicing the "four expressions of life"

(1) Expression of love: Convey love to family and friends.

(2) Expression of gratitude: Thank those who have provided support.

(3) Expression of apology: Address past regrets and misunderstandings.

(4) Expression of farewell: Peacefully bid farewell to life stages or challenges.

7.3. Seeking spiritual guidance

Spiritual mentors or religious figures: Seek guidance from pastors, spiritual mentors, or other advisors to explore life's meaning and address spiritual concerns.

7.4. Engaging in helping and charitable activities

(1) Helping others: Within one's capacity, offer care and assistance to those in need.

(2) Participating in charitable causes: Involve oneself in public welfare activities to foster inner happiness and a sense of accomplishment through selfless contribution.

7.5. Practicing kindness and self-development

(1) Spiritual explanation: Everyone harbors inherent kindness ("angel") and occasional negative impulses ("devil"). Cultivating kindness forms the foundation for spiritual growth.

(2) Empathy and compassion: Show concern and empathy for the suffering of others.

(3) Gratitude: Approach life with a thankful attitude.

(4) Altruism and universal love: Enrich life's meaning through selfless acts.

(5) Pursuit of truth, goodness, and beauty: Face life with sincerity and positivity.

(6) Small acts of kindness in daily life: Start with small deeds, such as helping those around you or contributing actively to society.

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Chapter 6

Common Pain Relief Methods

1. Introduction

1.1. Pain is a subjective experience that varies from person to person, encompassing both sensory perception and emotional experience. It includes physical injury, psychological/mental trauma, lack of support from family/society/economy, and the cognitive, interpretive, and emotional aspects of pain in spiritual/religious/cultural contexts.

1.2. When assessing or treating pain in palliative or terminally ill patients (referred to as palliative patients), the concept of "total pain or total suffering" should be applied. This involves evaluating and addressing pain from multiple perspectives with corresponding treatment plans.

1.3. Treating pain in palliative patients usually requires a collaborative effort among multidisciplinary experts, patients, families, and caregivers.

2. Common pain management methods for palliative patients

2.1. Treatment of physical diseases/tumor (especially for acute conditions like fractures, nerve compression, respiratory emergencies, thoracic emergencies, brain emergencies): Surgical treatments, chemotherapy, radiotherapy, and other treatments.

2.2. Pain medication treatments: Various pain medications, antidepressants, anticonvulsants, local anesthetics, and other medications.

2.3. Neural blockade procedures: Temporary nerve blocks, nerve stimulation, nerve resection or neurolysis, and other procedures.

2.4. Rehabilitation therapy: Use of assistive devices, hydrotherapy, instrumental therapy, and other treatments.

2.5. Other therapies: Complementary therapies, alternative therapies, and integrative medical therapies.

Note: In addition to the above treatment methods, psychological therapy, strengthening interpersonal support, and enhancing spiritual support should also be emphasized for palliative patients.

3. Common pain types and recommended treatments for palliative patients

Diagnosing and treating pain (physical pain) in palliative patients should be conducted by specialist physicians. The following information is for reference and suggestions only.

3.1. Bone pain and common treatment recommendations

(1) Pain characteristics: Dull/aching pain at the affected site, which may worsen with movement. Sudden onset of pain may indicate a fracture.

(2) Treatment: Bone alignment/supportive surgery.

(3) Medication recommendations:

- Nonsteroidal anti-inflammatory drugs (NSAIDs).
- Bisphosphonates.
- Steroid therapy.

(4) Radiation therapy: The primary choice for bone metastasis in cancer patients.

(5) Other therapies.

3.2. Visceral pain and common treatment recommendations

(1) Pain characteristics: Dull or colicky pain, often with unclear pain points.

(2) Constipation: Use of stool softeners and suppositories.

(3) Abdominal colic: Use of anticholinergic drugs.

(4) Gastric discomfort: Use of gastric acid inhibitors.

(5) Liver capsule pain: Treatment with NSAIDs or steroids combined with gastric acid inhibitors.

(6) Ascites: Use of drainage, diuretics, or chemotherapy.

(7) Bladder spasms: Treatment with antispasmodics.

3.3. Headache and common treatment recommendations

(1) Differentiation: Determine if the headache is primary (e.g., migraine) or secondary (e.g., due to intracranial lesions).

(2) Primary headache: Treatment with acetaminophen or other pain medications, massage, psychological therapy, spiritual care, and support.

(3) Morning headache with vomiting: Consider increased intracranial pressure and the possibility of intracranial lesions (e.g., brain metastasis from cancer). Treatment may involve intravenous steroids or intracranial tumor reduction/removal surgery.

(4) Other therapies.

3.4. Muscle spasm pain and common treatment recommendations

(1) Pain characteristics: Pain caused by muscle tightening and spasms.

(2) Treatment: Use of heat packs and massage.

(3) Medications: Use of central-type muscle relaxants to reduce muscle tension.

(4) Use NSAIDs.

3.5. Wound pain and common treatment recommendations

(1) Pain characteristics: Pain due to wound ulceration, pressure sores, or local tumor invasion.

(2) Treatment: Debridement.

(3) Local anesthetics: Use of local anesthetic sprays.

(4) Pain medications: Use of pain relief medications.

3.6. Neuropathic pain and common treatment recommendations

(1) Pain characteristics: Burning, stabbing, or shooting pain, often resulting from nerve tissue injury, possibly accompanied by sympathetic nervous system changes.

(2) Medications:

- Tricyclic antidepressants.
- Antiepileptic drugs.

(3) Procedures: Temporary nerve plexus block or permanent neurolysis for terminally ill patients.

4. Pain management recommendations for terminally ill patients

4.1. Not all patients will experience pain in their final stages of life, but if pain is present, it should be addressed promptly and effectively.

4.2. Common causes of pain include:

(1) Persistent pathological fractures.

(2) Oral candidiasis (which can cause pain in the mouth and throat).

(3) Urinary retention or constipation.

(4) Pressure ulcers.

(5) Pre-existing chronic pain or newly occurring acute pain conditions (such as brain, cardiovascular, thoracic, or abdominal emergencies).

4.3. Provide appropriate treatment based on the cause of the pain.

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Chapter 7

Non-Pharmacological Treatment

1. Introduction

1.1. Pain is a subjective experience that varies from person to person, encompassing both sensory perception and emotional experience. This includes physical injury, psychological trauma, the support (or lack thereof) from family, society, and economy, as well as the cognitive, interpretive, and emotional aspects of pain in spiritual, religious, and cultural contexts.

1.2. Patients receiving palliative care or in the terminally ill stage (hereafter referred to as palliative patients) often experience pain and should be properly cared for.

1.3. When assessing or treating pain in palliative patients, the concept of "total pain or total suffering" should be applied, evaluating and addressing each aspect with corresponding treatment plans.

1.4. Effective treatment of pain in palliative patients usually requires the collaboration of multidisciplinary experts, patients, families, and caregivers.

1.5. This chapter focuses on non-pharmacological treatments for pain management.

2. Goals of pain management

The goals are to treat curable diseases and the causes of pain. For incurable diseases or pain causes, the aim is to at least alleviate (or partially alleviate) the pain, with the hope of restoring (or partially restoring) the patient's physical and daily functions and enhancing their quality of life.

3. Methods of pain management

In medical care, it is advisable to adopt a multidisciplinary team approach for treating curable diseases or pain causes and alleviating pain. The main treatment methods are as follows:

3.1. Physical therapies:

  (1) Treatment of physical diseases/tumor treatment
  (2) Pain medication treatment
  (3) Neural blockade procedures
  (4) Rehabilitation therapy
  (5) Other therapies

3.2. Psychological/spiritual therapies: Cognitive-behavioral therapy, mindfulness therapy, spiritual care (religious, spiritual), and support, as well as other treatments.

3.3. Enhancing family/social support: Strengthening family, social, and economic support.

4. Treatment of physical pain and diseases

4.1. Treatment of physical/tumor conditions: Treat curable causes of pain, especially acute conditions such as fractures, nerve compression, respiratory emergencies, intracranial emergencies, thoracic emergencies, and abdominal emergencies. This includes surgery, radiotherapy, and chemotherapy.

4.2. Neural blockade procedures: Temporary nerve blocks to interrupt the vicious cycle of pain, such as using nerve stimulation, or permanent neurolysis to terminate various types of neuropathic pain.

4.3. Exercise or rehabilitation therapy:

(1) Patient-self-directed activities/exercises:

- Chronic pain often limits the range of motion in limbs/joints, leading to stiffness and increased pain. Appropriate levels of activity/exercise can improve this type of pain.
- Proper activities/exercises can also enhance/improve the functions of bodily organs and systems, including cardiovascular, pulmonary, gastrointestinal, sympathetic, and parasympathetic systems, normalize hormone secretion, improve mood, and reduce depression/anxiety and pain perception.
- Start with 1-2 light activities/exercises based on physical condition, then gradually increase the duration and variety of activities/exercises as physical condition improves.

(2) Hospital-based rehabilitation therapy:

- Exercise therapy
- Hydrotherapy
- Instrumental therapy
- Manual therapy
- Traction therapy
- Assistive device therapy

(3) Complementary, alternative, and integrative medical therapies: Examples include yoga, tai chi, massage, traditional Chinese medicine, acupuncture, and nutritional therapy.

5. Psychological/mental/spiritual therapies

5.1. Patient self-regulation methods

(1) Reducing psychological/mental stress and distress

- Simple, slow deep breathing exercises—inhaling slowly and exhaling slowly, repeated several times—can effectively reduce tension.
- Sitting, lying down, or leaning against a wall or pillar, relaxing for a moment can also help reduce tension.
- Mindfulness meditation:

☆Find a quiet place.

☆Sit or lie down and take a deep breath.

☆Think positively and consider the potential good outcomes of a situation.

☆Temporarily clear your mind of all current matters.

☆Reflect on pleasant past experiences, giving yourself a mental vacation.

(2) Maintaining good sleep quality

- Pain can disrupt sleep quality, and poor sleep can exacerbate pain, creating a vicious cycle.
- Creating good sleep quality:

☆Create a sleep-friendly environment.

☆ Maintain a regular daily routine.

☆ Go to bed at a fixed time in a comfortable, warm, and relaxed state.

☆ Avoid consuming caffeine, tea, smoking, and other stimulants before bedtime.

☆ Use relaxation, deep breathing, and mindfulness meditation techniques to clear your mind and induce sleep.

(3) Enriching the spirit (spiritual support)

- Enriching the spiritual ledger: Like a bank or health ledger, people have a "spiritual ledger" of joy/happiness. Building many happy memories strengthens the spirit and helps overcome physical and mental discomfort.
- Cultivating gratitude: Daily meditation or expressing gratitude for people and events several times a day can strengthen the spirit and emotions, gain support from others, and harmonize one's life.
- Cultivating contentment: Spend time each day reflecting on and appreciating the good people, events, and things around you. A sense of contentment can improve mood and strengthen the spiritual ledger.

- Religious faith: Having religious faith can enhance inner hope and strength.
- Detailed psychological/mental therapies: Refer to Chapter 12: Psychological/Mental, Social, and Spiritual Support.

5.2. Hospital-provided psychological therapies

(1) Cognitive Behavioral Therapy (CBT): This therapy focuses on helping patients recognize how pain-induced negative thoughts affect emotions, informing them about pain causes, risk factors, prevention, and improvement methods. It teaches patients the necessary activities and exercises to overcome pain and encourages practical application.

(2) Acceptance and Commitment Therapy (ACT): This therapy promotes cognitive flexibility (reframing thoughts and adapting to changes) and supports individuals in taking action to pursue value-oriented goals.

(3) Relaxation training: Techniques include meditation, abdominal breathing, progressive muscle relaxation, and guided imagery. These methods are useful treatment models for many patients with long-term/ chronic pain.

(4) Other therapies: Additional methods may also be employed based on the patient's specific needs and conditions.

6. Strengthening family/social support

Through explanation and communication by medical personnel, patients and their families can understand the following to enhance the patient's family and social support:

6.1. Understanding palliative care and related support.

6.2. Understanding the legal regulations in palliative care.

6.3. Understanding the causes of pain.

6.4. Expressing pain.

6.5. Choosing appropriate pain relief methods.

6.6. Understanding the advantages and disadvantages of common pain medications.

6.7. Safely choosing and using opioid medications.

6.8. Patient self-care practices.

6.9. Medical care considerations at the end of life.

6.10. Matters that family members and caregivers can assist with or should be aware of.

6.11. Spiritual comfort at the end of life, grief support, and care for the bereaved.

6.12. How to seek assistance.

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Chapter 8

Non-Opioid Analgesic Therapy

1. Introduction

1.1. Patients receiving palliative care or at the end of life (hereafter referred to as palliative patients) often have weakened physical conditions, and their organ functions may not be in a healthy state. Therefore, when using analgesics to treat pain, attention should be paid to the dosage and monitoring of side effects.

1.2. In medical practice, non-opioid analgesics used for pain management in palliative patients (including terminal cancer patients) include acetaminophen, non-steroidal anti-inflammatory drugs (NSAIDs), antidepressants, anticonvulsants, local analgesics, corticosteroids, and other topical medications.

2.Acetaminophen

2.1. Efficacy: Treats mild to moderate pain and has antipyretic effects.

2.2. Applicable conditions: Acute or chronic pain caused by injury to muscles, bones, or other non-neural tissues.

2.3. Side effects/contraindications:

(1) Caution should be taken regarding its hepatotoxicity; for adults with normal liver function, the maximum daily limit is 4 grams. However, the dosage should be reduced when used in palliative patients.

(2) In palliative patients, those with cachexia, patients undergoing chemotherapy, those with liver tumors or liver metastasis, or in cases of liver dysfunction, the dosage should be used with caution or reduced.

3. Non-Steroidal Anti-Inflammatory Drugs (NSAIDs)

3.1. Efficacy: Treats mild to moderate pain and has anti-inflammatory and antipyretic effects.

3.2. Applicable conditions: Acute or chronic pain caused by injury to muscles, bones, or other non-neural tissues, recommended for short-term use.

3.3. Side effects/contraindications:

(1) In palliative patients and those with cachexia, use with extra caution.

(2) Gastrointestinal toxicity:

- High-risk groups: Individuals over 60 years old, those with a history of peptic ulcers, concurrent use of corticosteroids, and long-term aspirin users.

- During the use of these drugs, if patients develop peptic ulcers, gastrointestinal bleeding, or worsened liver function, the use of these drugs should be stopped immediately.

(3) Hematologic toxicity:

- When used concurrently with anticoagulants, it enhances the effects of the anticoagulants, leading to a risk of bleeding.
- Not recommended to be used with aspirin.

(4) Renal toxicity:

- High-risk groups: Individuals over 60 years old, those with dehydration, multiple myeloma, diabetes, kidney disease, or those using nephrotoxic chemotherapy drugs.
- During the use of these drugs, if patients develop worsened kidney function or hypertension, the dosage should be reduced.

(5) Cardiotoxicity:

These drugs may have cardiotoxic effects and are not recommended for use in patients with heart failure or hypertension.

3.4. Commonly used medications: (We list only the active ingredients of medications): indomethacin, methyl salicylate, etofenamate, diclofenac, piroxicam, niflumic acid, flurbiprofen.

Note: The following medications have less gastrointestinal, renal, and hematologic toxicity but still require attention to their cardiotoxic effects: celecoxib, etoricoxib, and parecoxib.

4. Antidepressants

4.1. Efficacy: Used to treat various types of neuropathic pain, including those caused by cancer and non-cancer conditions.

4.2. Applicable conditions:

(1) Various types of non-cancer neuropathic pain.

(2) Neuropathic pain caused by chemotherapy or radiation therapy.

(3) Neuropathic pain due to nerve inflammation caused by tumor compression.

4.3. Side effects/contraindications:

(1) Use with caution in palliative patients, those with cachexia, and patients with cognitive impairment.

(2) Dosage should be reduced in patients with impaired liver or kidney function.

(3) Common side effects: drowsiness, weakness, agitation, insomnia, blurred vision, difficulty urinating, orthostatic hypotension, cardiac conduction abnormalities, weight gain, and sexual dysfunction.

(4) Use with caution in patients with arrhythmias, recent history of myocardial infarction, heart block, epilepsy, narrow-angle glaucoma, hyperthyroidism, urinary retention, and those taking monoamine oxidase inhibitors (MAOIs).

(5) Patients should avoid operating machinery or driving and should not consume alcohol while taking these medications.

4.4. Commonly used medications: (We list only the active ingredients of medications) : amitriptyline, imipramine, nortriptyline, desipramine.

5. Anticonvulsants

5.1. Efficacy: Used to treat various types of neuropathic pain, including those caused by cancer and non-cancer conditions.

5.2. Applicable conditions:

(1) Various types of non-cancer neuropathic pain.

(2) Neuropathic pain caused by chemotherapy or radiation therapy.

(3) Neuropathic pain due to nerve inflammation caused by tumor compression.

5.3. Side effects/contraindications:

(1) Use with caution in palliative patients, those with cachexia, and patients with cognitive impairment.

(2) Common side effects: drowsiness, weight gain, rash, dizziness, imbalance (unsteady gait), and gum swelling.

(3) Reduce dosage in older adults or those with renal impairment.

(4) Contraindications: Patients should avoid operating machinery or driving and should not consume alcohol while taking these medications.

5.4. Commonly used medications: (We list only the active ingredients of medications): gabapentin, carbamazepine, lamotrigine, pregabalin, topiramate, oxcarbazepine.

6. Use of local analgesics

6.1. Efficacy: Provides local pain relief.

6.2. Applicable conditions: Localized tissue pain, joint pain, muscle strain pain.

6.3. Side effects/contraindications: Few systemic and local side effects, but should be used on healthy, intact skin.

6.4. Commonly used medications:

(1) Patches and sprays containing local anesthetics.

(2) Patches, creams, gels, and sprays containing non-steroidal anti-inflammatory drugs (NSAIDs).

(3) Traditional Chinese medicine patches.

7. Corticosteroids

7.1. Efficacy: Treats tissue pain caused by acute inflammation, can be administered intravenously or intramuscularly.

7.2. Applicable conditions/Side Effects:

(1) Can be used to treat acute pain crises in palliative patients (including terminal cancer patients), but limited to short-term use.

(2) Also effective in treating severe nausea and vomiting caused by chemotherapy or radiation therapy.

(3) Due to many systemic side effects, usage is limited to short-term.

7.3. Commonly used medications: (We list only the active ingredients of medications): dexamethasone, prednisolone, triamcinolone, betamethasone, methylprednisolone, hydrocortisone, cortisone.

8. Recommended dosage of medications

Depending on the applicable conditions and contraindications of individual medications, as well as the information provided in the drug's instructions, appropriate medications and dosages should be used as directed by a physician. This should be based on the individual patient's situation, including age, gender, physical condition, organ function, cancer type, cancer stage, and the effectiveness of tumor treatment.

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Chapter 9

Opioid Therapy

1. Introduction

1.1. In 1986, the World Health Organization (WHO) introduced the three-step analgesic ladder for cancer pain management, which remains the most viable basic model for cancer pain treatment. It is also commonly used for pain management in palliative care or terminally ill patients (hereafter referred to as palliative patients).

(1) Step 1 (mild pain): Use non-opioid medications such as acetaminophen, aspirin, or non-steroidal anti-inflammatory drugs (NSAIDs), with the addition of adjuvant medications if necessary.

(2) Step 2 (mild to moderate pain): Use weak opioids such as codeine and tramadol, with the addition of Step 1 medications if necessary.

(3) Step 3 (moderate to severe pain): Use strong opioids such as morphine and fentanyl, with the addition of Step 1 medications if necessary.

Note: According to the 2012 WHO guidelines, the appropriate step and analgesic can be selected directly based on the severity of the pain, without following a step-by-step progression. At Step 2, low doses of strong opioids can also be used directly.

1.2. Opioid medications are primarily administered orally. However, if oral administration is not suitable, other routes of administration may be used. In terminally ill patients, subcutaneous infusion is also a common method.

1.3. It is not recommended to use two different opioids simultaneously via the same route of administration.

1.4. If it is anticipated that a patient's pain will escalate from moderate to severe in the near future, strong opioids can be used directly.

1.5. For patients with long-standing pain (usually lasting several weeks or more), long-acting opioids can be considered.

1.6. The risk of opioid use disorder (commonly known as addiction) in palliative patients under normal medical use is extremely low. However, attention should be paid to the side effects of opioids, and preventive medication can be administered to avoid them. If side effects are difficult to manage, switching to a different opioid can be considered (for detailed information, refer to Chapter 10: Prevention and Management of Opioid Side Effects).

1.7. Proper use of opioids for pain management does not shorten a patient's life.

1.8. Detailed medication records help ensure proper pain management and the safety and comfort of the patient.

2. Important considerations when using opioid analgesics

2.1. When using opioid analgesics, the most common side effects include nausea, vomiting, constipation, sedation (drowsiness), delirium (confusion, disorientation), and itching. These side effects can be prevented or treated. If you experience any discomfort, please contact your prescribing physician.

2.2. Sedation (drowsiness) is the most common side effect of these medications. Most patients will feel sleepy after taking the medication. During this time, do not drive, operate machinery, or engage in activities that require mental effort. This drowsiness usually becomes less noticeable within 7-10 days as the patient develops tolerance to the medication. If the condition does not improve after 7-10 days, inform your doctor to investigate the cause.

2.3. Respiratory depression is the most serious side effect of opioids, but it only occurs with excessive dosing or in patients with poor respiratory function. Gradual dose adjustments of opioids can prevent this condition. Even if mild respiratory depression occurs, it typically resolves with continued treatment (about 1-3 weeks). Long-term use of opioids for pain management does not cause respiratory depression unless the patient's condition changes (worsened respiratory function) or the dosage is increased.

2.4. Combining opioids with alcohol or sedative-hypnotics can lead to overdose, resulting in slurred speech, erratic behavior, unsteady gait, slow breathing, confusion, cyanosis, coma, or even death. Avoid alcohol while using opioids.

2.5. When used as prescribed, the risk of addiction to opioids is very low. However, patients with a history of addiction to opioids, alcohol (excessive drinking), or other substances have a higher risk of addiction.

2.6. Use opioids as prescribed by your doctor. Do not adjust the route or dosage of the medication on your own. If a dosage reduction is needed, follow your doctor's instructions for a gradual and systematic reduction. Do not abruptly stop using the medication.

2.7. Do not share your opioid medication with family members or friends (others).

2.8. After obtaining opioid medication, store it properly to prevent loss or misuse by children. Return any unused medication to the original medical facility where you received it.

2.9. Do not chew extended-release oral tablets. Do not inject medications intended for non-injection use.

3. Important considerations for home use of individual opioid analgesics

The following information is partially based on the package inserts of the respective medications.

3.1. Important considerations for home use of morphine tablets

(1) Efficacy

Morphine is a powerful analgesic used for the relief of severe pain.

(2) Usage

- Swallow extended-release or immediate-release tablets whole. Do not chew or crush them.
- Swallow sustained-release capsules whole, or open the capsule and sprinkle the small granules onto a cold, non-alcoholic beverage and swallow immediately. Do not crush or chew the granules.

(3) Precautions

- Inform your doctor if you have a history of morphine allergy, liver dysfunction, respiratory depression, asthma, heart failure, arrhythmias, head injury, brain tumor, acute alcohol intoxication, or seizures. The doctor will assess whether morphine is suitable for you.
- Sudden discontinuation after continuous use or simultaneous use of opioid antagonists can lead to withdrawal symptoms such as tearing, sweating, nausea, vomiting, diarrhea, abdominal pain, dilated pupils, headache, insomnia, restlessness, delirium, tremors, muscle and joint pain, and rapid breathing.

- Do not use this medication if there is a possibility of paralytic ileus.
- Drowsiness may occur after taking the medication. Avoid activities that require full concentration or that may cause danger, such as driving or operating machinery.
- The safety of this medication for pregnant women has not been established. Inform your doctor if you are planning to become pregnant, are pregnant, or are breastfeeding. The doctor will assess whether morphine is suitable for you.

(4) Side effects

Respiratory depression, nausea, vomiting, facial flushing, palpitations, biliary spasm, constipation, insomnia, headache, hallucinations, urinary retention, itching, and hives.

(5) What to do if you miss a dose

If you are taking this medication regularly and forget to take a dose, take it as soon as you remember. If it is close to the time for your next dose, skip the missed dose and take the next dose at the regular time. Do not take a double dose to make up for the missed dose.

(6) Storage

Store the medication at room temperature. Avoid storing it in high-temperature or humid places.

3.2. Important considerations for home use of fentanyl transdermal patches

(1) Efficacy

Fentanyl transdermal patches are a potent analgesic absorbed through the subcutaneous microvasculature, providing pain relief. The medication is continuously released from the patch over 72 hours and absorbed into the systemic circulation to exert its analgesic effect.

(2) Usage

- Preparation before use

☆ The fentanyl transdermal patch should be applied to a normal, flat skin surface on the trunk or upper arm. For younger children, the upper back is a more ideal location.

☆ Before applying the patch, trim hair at the application site (preferably a hairless area) without shaving to avoid skin irritation.

☆ Clean the skin at the application site with clean water only. Do not use soap, oil, lotion, or other substances that may irritate or alter the skin.

☆ Allow the skin to dry completely before applying the patch.

- Application

☆ Remove the fentanyl patch from the sealed packaging (use immediately after removal).

☆ Remove the protective liner from the patch.

☆ Apply the patch to the skin and press it firmly with the palm of your hand for 30 seconds to ensure full contact, paying special attention to the edges. You can use breathable tape to secure the edges if necessary.

☆ Wash your hands with clean water after applying the patch.

- Removal

☆ Used patches should be placed in the original packaging and returned to the pharmacy along with the record sheet. Do not dispose of them casually.

☆ Unused patches should be returned to the pharmacy at the medical facility where you were treated.

- Precautions

☆ Check the integrity of the patch before use. Do not use cut, divided, or damaged patches.

☆ The patch can be worn for up to 72 hours continuously. After removal, apply a new patch to a different site. The same skin area should not be reused for about a week.

☆ Showering is allowed, but do not apply local heat or take baths to avoid accelerating drug release and absorption.

- Other information

☆ Follow your doctor's instructions on where to apply the patch, such as the chest, back, upper arm, or thigh (not necessarily at the pain site).

☆ The drug remains in the skin for up to 24 hours after the patch is removed, continuing to provide pain relief. Therefore, do not worry about immediate loss of effect and pain recurrence upon patch removal.

☆ When using the patch for the first time, pain relief may be slow as the drug needs to be absorbed through the skin. During the first 12-24 hours after applying the patch, continue taking oral pain medications. If transitioning from oral pain medications to patches, apply the patch with the last dose of oral medication.

☆ For breakthrough pain, follow your doctor's instructions for using other fast-acting pain medications (e.g., buccal tablets or sublingual tablets).

● Side effects

☆ Common side effects include slowed breathing, nausea, vomiting, constipation, sedation, and drowsiness. Keep a record of side effects and inform your doctor during visits.

☆ Seek immediate medical attention for severe side effects such as allergic reactions, inability to breathe, muscle spasms, persistent chest pain, or irregular heartbeats.

● What to do if you miss a dose

☆ If you forget to change the patch, remove the old patch and apply a new one as soon as you remember.

☆ Do not apply a double dose.

● Storage

Store the medication in its unopened original packaging at a temperature below 25°C.

3.3. Important considerations for home use of fentanyl buccal films

(1) Efficacy

Fentanyl buccal films are a potent analgesic absorbed through the oral mucosa, used for managing breakthrough pain in cancer patients.

(2) Usage

- Opening the fentanyl buccal films:

☆ Hold the aluminum foil package with the back facing you and use scissors to cut along the arrow.

☆ Repeat the above steps to cut the other side of the package.

☆ Peel apart the two layers of the aluminum foil package and take out the buccal film.

- Using the fentanyl buccal films:

☆ Moisten the inside of your cheeks with your tongue or rinse your mouth with water to wet the area where the film will be placed.

☆ Place the buccal film on a clean, dry fingertip with the pink side facing up.

☆ Place the buccal film in your mouth with the pink side against the moistened inside of your cheek. Press and hold it in place for 5 seconds to ensure it adheres.

☆ Keep the buccal film in place until it dissolves (usually within 15-30 minutes).

(3) Precautions

- Do not chew or swallow the fentanyl buccal film; do not cut or tear the film.
- Open the packaging only immediately before use.
- You can drink liquids 5 minutes after applying the buccal film.
- Avoid touching or moving the film with your tongue or fingers before it dissolves, and avoid eating.

- There should be at least a 2-hour interval between using the buccal film for new episodes of breakthrough pain.
- Continue using your regular opioid pain medication while using the buccal film.
- If you need to use the buccal film more than four times a day, consult your doctor, as there may be a need to adjust the dosage of your regular opioid pain medication.

(4) Side effects

Common side effects include dizziness, nausea, vomiting, drowsiness, constipation, sweating, and shortness of breath.

(5) Storage

Store the medication at room temperature. Avoid storing it in high-temperature or humid places.

3.4. Important considerations for home use of fentanyl buccal tablets

(1) Efficacy

Fentanyl buccal tablets are a potent analgesic absorbed through the oral mucosa, used for managing breakthrough pain in cancer patients.

(2) Usage

- Opening the fentanyl buccal tablets:

☆ Follow the instructions on the packaging to remove the tablet. Tear along the perforations to extract the tablet from the aluminum foil.

☆ Do not push the tablet through the foil packaging, as this may damage the tablet.

☆ Once removed from the packaging, use the tablet immediately.

- Using the buccal tablets:

☆ Place the tablet between the cheek and gum above a rear molar (in the buccal cavity) or place the entire tablet under the tongue until it disintegrates, which usually takes about 14 to 25 minutes.

☆ If there is any residual tablet left after 30 minutes, it can be swallowed with a glass of water.

☆ If using multiple times a day, alternate sides of the mouth.

(3) Precautions

- Do not crush, inhale, chew, or swallow the fentanyl buccal tablet whole.
- Open the packaging only immediately before use to avoid damaging the tablet or unnecessary exposure.
- If breakthrough pain is not relieved after 30 minutes, another dose of the same strength can be used to treat the same episode. Do not use the buccal tablet more than twice for any single pain episode.
- There should be at least a 4-hour interval before using the buccal tablet for a new episode of breakthrough pain.
- Continue using your regular opioid pain medication while using the buccal tablet.
- If experiencing more than four breakthrough pain episodes per day, consult your doctor, as the dosage of your regular opioid pain medication may need to be adjusted.

- During the initiation and dose adjustment period, closely monitor for respiratory depression. Seek immediate medical attention if breathing difficulties occur.
- Avoid alcohol during the treatment period to prevent respiratory depression.
- The buccal tablet may impair the ability to perform hazardous activities. Avoid driving or operating dangerous machinery.
- The buccal tablet may cause orthostatic hypotension and fainting. Take care when rising from a sitting or lying position.

(4) Side effects

Common side effects include dizziness, nausea, vomiting, drowsiness, constipation, sweating, and shortness of breath.

(5) Storage

Store the medication at room temperature. Avoid storing it in high-temperature or humid places.

3.5. Important considerations for home use of oxycodone

(1) Efficacy

Oxycodone is a potent analgesic used for the relief of moderate to severe pain.

(2) Usage

If using extended-release tablets, swallow them whole. Do not crush, chew, or dissolve, as this can lead to rapid release and absorption of a potentially fatal dose.

(3) Precautions

- Inform your doctor if you have liver or kidney dysfunction, severe respiratory depression, asthma, head injury, chronic obstructive pulmonary disease (COPD), epilepsy, or suspected paralytic ileus and gastrointestinal obstruction. Your doctor will assess whether oxycodone is suitable for you.
- You may feel drowsy or have lowered blood pressure after taking the medication. Avoid activities that require full concentration or that may cause danger, such as driving or operating machinery.
- Inform your doctor or pharmacist if you are taking other medications, especially sedatives, sleeping pills, or muscle relaxants.
- The safety of this medication for pregnant women has not been established. If you are planning to become pregnant, are pregnant, or are breastfeeding, inform your doctor, who will assess whether oxycodone is suitable for you.

(4) Side effects

Common side effects include constipation, nausea, drowsiness, vomiting, fatigue, headache, dizziness, abdominal pain, breathing difficulties, rapid heartbeat, and low blood pressure.

(5) What to do if you miss a dose

If you are taking this medication regularly and forget to take a dose, take it as soon as you remember. If it is close to the time for your next dose, skip the missed dose and take the next dose at the regular time. Do not take a double dose to make up for the missed dose.

(6) Storage

Store the medication at room temperature. Avoid storing it in high-temperature or humid places.

3.6. Important considerations for home use of buprenorphine transdermal patches

(1) Efficacy

Buprenorphine transdermal patches are a potent analgesic absorbed through the subcutaneous microvasculature to exert its effect. The analgesic effect appears 12-24 hours after application, peaks at about 3 days, and can last up to 96 hours. It is used for the relief of moderate to severe pain.

(2) Usage

- Choose a clean, hairless, flat skin area, avoiding sites with large scars. The upper back or subclavicular area of the chest is preferred.
- Wash the application area with clean water, avoiding soap or other cleansers. Ensure the skin is completely dry before applying the patch.
- Apply the patch immediately after removing it from the package, pressing it firmly with the palm for about 30 seconds.

(3) Warnings and precautions

- Apply each new buprenorphine patch to a different skin site; the same site should not be reused for at least 3 weeks.
- The patch can be worn continuously for up to 4 days and can be replaced twice a week at regular intervals (e.g., Monday morning and Thursday evening).

- Do not use more than one patch at a time, regardless of the dosage strength.
- The patch is not affected by bathing, showering, or swimming but should not be exposed to high heat (e.g., sauna, infrared lamps) to avoid excessive drug release.
- The patch is a special sustained-release formulation and should not be cut, as this will compromise its efficacy.
- Since studies on patients under 18 years old are not available, it is not recommended for use in this age group.
- Pregnant or breastfeeding women should not use this patch.
- Severe respiratory depression may occur; use with caution in patients with impaired respiratory function.
- At the start of treatment, when changing doses, or when used in combination with substances that affect mental status (including alcohol, sedatives, and sleeping pills), dizziness, drowsiness, blurred vision, or double vision may occur. Patients experiencing these symptoms should not drive or operate machinery during the use of the patch and for at least 24 hours after removal.

(4) Side effects

Common side effects include dizziness, headache, drowsiness, nausea, constipation, local itching, vomiting, and redness at the application site.

(5) Storage

Store the medication at room temperature. Avoid storing it in high-temperature or humid places.

3.7. Important considerations for home use of buprenorphine sublingual tablets

(1) Efficacy

Buprenorphine sublingual tablets are a potent analgesic absorbed through the sublingual microvasculature, used for the relief of moderate to severe pain.

(2) Usage

Place the tablet under the tongue and allow it to dissolve completely for absorption. Do not chew or swallow the tablet. Follow the prescribed dosage and instructions from your doctor.

(3) Precautions

- Inform your doctor if you have kidney disease, head injury, increased intracranial pressure, cardiovascular disease, or gastrointestinal disorders. The doctor will assess whether buprenorphine is suitable for you.
- You may feel drowsy after taking the medication. Avoid activities that require full concentration or that may cause danger, such as driving or operating machinery.
- Do not consume alcohol during the medication period. Inform your doctor or pharmacist if you are taking other medications, especially sedatives, sleeping pills, or antihistamines.
- The safety of this medication for pregnant women has not been established. If you are planning to become pregnant, are pregnant, or are breastfeeding, inform your doctor, who will assess whether buprenorphine is suitable for you.

- After taking the medication, wait until the tablet is completely dissolved in the oral mucosa before drinking water to rinse your mouth gently. Wait at least one hour before brushing your teeth.

(4) Side effects

Common side effects include edema, dizziness, drowsiness, weight gain, blurred vision, constipation, and dry mouth.

(5) What to do if you miss a dose

If you are taking this medication regularly and forget to take a dose, take it as soon as you remember. If it is close to the time for your next dose, skip the missed dose and take the next dose at the regular time. Do not take a double dose to make up for the missed dose.

(6) Storage

Store the medication at room temperature. Avoid storing it in high-temperature or humid places.

3.8. Important considerations for home use of codeine tablets

(1) Efficacy

Codeine is a mild analgesic primarily used for cough suppression and pain relief.

(2) Usage

Follow the prescribed dosage and instructions from your doctor. Do not increase the dosage or frequency of use without your doctor's approval.

(3) Precautions

This medication may cause drowsiness. Do not drive or operate dangerous machinery after taking the medication.

(4) Side effects

Side effects are uncommon but may include constipation, nausea, vomiting, and headache.

(5) What to do if you miss a dose

If you are taking this medication regularly and forget to take a dose, take it as soon as you remember. If it is close to the time for your next dose, skip the missed dose and take the next dose at the regular time. Do not take a double dose to make up for the missed dose.

(6) Storage

Store the medication at room temperature. Avoid storing it in high-temperature or humid places.

3.9. Important considerations for home use of tramadol

(1) Efficacy

Tramadol is a mild analgesic used for pain relief.

(2) Usage

If using extended-release tablets or sustained-release formulations, swallow them whole. Do not crush or split the tablets.

(3) Precautions

- When used in combination with central nervous system medications (e.g., sedatives, sleeping pills), the sedative and analgesic effects may be enhanced. Use with caution.
- This medication is contraindicated for patients allergic to its components and for those with acute alcohol intoxication, sleeping pill, analgesic, or psychotropic drug intoxication.

- This medication is not recommended for use during pregnancy. Inform your doctor if you are planning to become pregnant, are pregnant, or are breastfeeding, so they can assess if it is suitable for you.
- This medication is not suitable for children under 12 years old.

(4) Side effects

Common side effects include dizziness, headache, drowsiness, constipation, nausea, vomiting, dry mouth, and gastrointestinal discomfort.

(5) What to do if you miss a dose

If you are taking this medication regularly and forget to take a dose, take it as soon as you remember. If it is close to the time for your next dose, skip the missed dose and take the next dose at the regular time. Do not take a double dose to make up for the missed dose.

(6) Storage

Store the medication at room temperature. Avoid storing it in high-temperature or humid places.

3.10. Important considerations for home use of tramadol and acetaminophen combination

(1) Efficacy

This combination medication includes a mild opioid analgesic (tramadol) and a centrally acting analgesic (acetaminophen). The synergistic effect of these two medications with different mechanisms of action is used to treat moderate to severe pain that is not relieved by non-opioid analgesics.

(2) Usage

Follow the prescribed dosage and instructions from your doctor. Do not increase the dosage or frequency of use without your doctor's approval.

(3) Precautions

- When used in combination with central nervous system medications (e.g., sedatives, sleeping pills), the sedative and analgesic effects may be enhanced. Use with caution.
- This medication is contraindicated for patients allergic to its components and for those with acute alcohol intoxication, sleeping pill, analgesic, or psychotropic drug intoxication.
- Inform your doctor if you have liver disease, so they can assess whether this medication is suitable for you.
- Avoid alcohol while taking this medication. Inform your doctor if you have a habit of heavy drinking.
- This medication is not recommended for use during pregnancy. Inform your doctor if you are planning to become pregnant or are pregnant, so they can assess whether this medication is suitable for you.
- This medication is not suitable for children under 12 years old.
- If you are also taking other medications containing acetaminophen for pain relief, fever, or cold symptoms, inform your doctor or pharmacist to avoid exceeding the recommended dose.

(4) Side effects

Common side effects include dizziness, headache, drowsiness, constipation, nausea, vomiting, dry mouth, gastrointestinal discomfort, rash, and tinnitus.

(5) What to do if you miss a dose

If you are taking this medication regularly and forget to take a dose, take it as soon as you remember. If it is close to the time for your next dose, skip the missed dose and take the next dose at the regular time. Do not take a double dose to make up for the missed dose.

(6) Storage

Store the medication at room temperature. Avoid storing it in high-temperature or humid places.

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Chapter 10

Prevention and Management of Opioid-related Side Effects

1. Introduction

1. Introduction (summary of important risks associated with opioid use)

1.1. Risk of respiratory depression from opioid use

(1) Opioids can directly act on the brainstem's respiratory centers, causing respiratory depression, carbon dioxide retention, and enhancing the sedative effects of opioids.

(2) Severe respiratory depression can be life-threatening.

1.2. Risks in patients with chronic obstructive pulmonary disease (COPD), cachexia, or frailty

(1) Patients with severe COPD or cor pulmonale have significantly reduced respiratory reserve, and hypoxia and hypercapnia lower their tolerance to opioids, increasing the risk of respiratory depression and potentially leading to life-threatening situations. Use with caution or avoid use.

(2) Elderly, cachectic, or critically ill patients also have reduced opioid tolerance, increasing the risk of life-threatening conditions. Use with caution or avoid use.

1.3. Risks when combined with benzodiazepines or other central nervous system (CNS) depressants (including alcohol)

(1) Combining opioids with benzodiazepines or other CNS depressants (including alcohol) can lead to severe sedation, respiratory depression, coma, and death. Avoid concurrent use.

(2) If opioids must be added to a patient already using benzodiazepines, use a lower dose.

1.4. Risks in patients with increased intracranial pressure, brain tumors, head injury, or impaired consciousness

(1) Opioids can cause carbon dioxide retention, further increasing intracranial pressure, so use with caution.

(2) Opioids can also cause sedation, making the clinical course of head injury patients difficult to observe. Avoid use in patients with impaired consciousness or coma.

1.5. Risks in patients with gastrointestinal and biliary diseases

(1) Opioids are contraindicated in patients with known or suspected gastrointestinal obstruction, including tumor-induced intestinal obstruction or paralytic ileus.

(2) Opioids can cause spasm of the sphincter of Oddi, worsening biliary obstruction diseases like acute cholecystitis and acute pancreatitis. Avoid use.

1.6. Risks in patients with cardiovascular disease

(1) Opioids can cause hypotension or, in rare cases, hypertension, and may cause tachycardia or bradycardia.

(2) Use with caution in patients with cardiovascular disease and closely monitor their cardiovascular function.

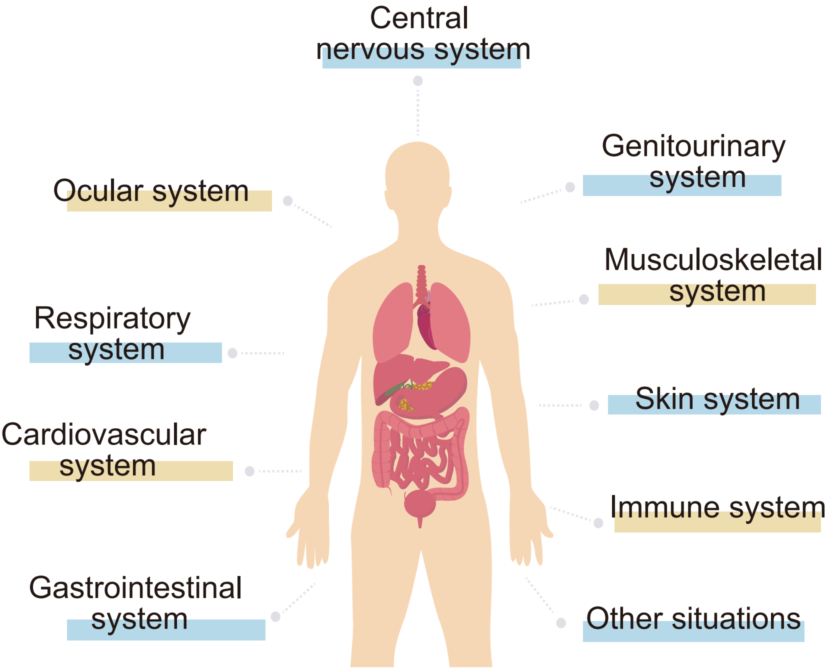
1.7. Risks in driving and operating machinery

(1) Patients should avoid driving or operating machinery during initial use or dose adjustments of opioids.

(2) In other situations, patients should assess their response and coping ability but should remain cautious.

2. Potential side effects of opioid use on individual organ systems

Using opioids may cause side effects on the following organ systems:



2.1. Central nervous system (brain)

(1) Euphoria.

(2) Drowsiness, sedation, or sleep disorders (e.g., insomnia or hypersomnia).

(3) Hallucinations.

(4) Restlessness and agitation.

(5) Dizziness, headaches, and even seizures.

(6) Delirium.

(7) Depression.

(8) Cognitive impairment (e.g., memory, attention, decision-making, and reaction).

(9) Hyperalgesia.

(10) Abnormal drug-seeking behavior (opioid use disorder).

2.2. Ocular system

(1) Pupil constriction.

(2) Pupil constriction even in dark environments.

(3) Pupil dilation in cases of concurrent brain hypoxia.

2.3. Respiratory system

(1) Respiratory depression, the most severe adverse effect, which may result from overdose.

(2) Greatly increased risk of respiratory depression and death when combined with benzodiazepines, other central nervous system depressants, or alcohol.

2.4. Cardiovascular system

(1) Lowered blood pressure.

(2) Peripheral edema (swelling of limbs).

2.5. Gastrointestinal system

(1) Constipation, nausea, and vomiting.

(2) Delayed gastric emptying.

2.6. Genitourinary system

(1) Urinary retention.

(2) Decreased levels of testosterone in men and estrogen in women.

(3) The medication crosses the placenta and is excreted in breast milk.

2.7. Musculoskeletal system

(1) Skeletal muscle rigidity (tight contraction), leading to breathing difficulties, especially when fentanyl is administered intravenously.

(2) Osteoporosis.

2.8. Dermatologic system

(1) Itching.

(2) Can occur with intravenous, intramuscular, or subcutaneous injections.

(3) Can also occur with intrathecal or epidural administration, though the mechanisms differ.

2.9. Immune system

Long-term use may suppress the immune system.

2.10. Other conditions

(1) Tolerance.

(2) Physical dependence.

(3) Addiction.

(4) Death.

3.Prevention and treatment of common side effects

The following management strategies are commonly used in medical practice:

3.1. Constipation

(1) Prevention

- Patients regularly taking opioids almost always need to prevent constipation, as this side effect does not develop tolerance and the risk of constipation remains long-term.
- Prophylactic use of stool softeners or stimulant laxatives is recommended. Increase the dose of these medications as the daily opioid dosage increases.
- Encourage patients to drink adequate amounts of water daily.
- Encourage patients to consume high-fiber fruits and vegetables daily.
- Encourage patients to exercise to promote bowel motility.

(2) When constipation occurs

- Check for other causes (differential diagnosis), such as the effects of other medications, tumor-related issues, or intestinal obstruction.
- Administer a mild laxative.
- Add other adjuvant analgesics to reduce opioid usage.

(3) If constipation persists

- Check for intestinal obstruction and identify any other causes.
- Administer stronger laxatives, possibly via rectal administration, but be aware of the side effects.
- Consider adding other pain relief methods or treatments to reduce pain and decrease opioid usage.
- Consider switching between different opioids.

3.2. Respiratory depression

When respiratory depression (<10 breaths/min) occurs

(1) Identify the cause (differential diagnosis), such as cardiac, pulmonary, or other organ failure, brain lesions, or concurrent use of other sedatives.

(2) Reduce the dosage of the opioid.

(3) Increase monitoring of respiratory function.

(4) If necessary, administer an opioid antagonist intravenously to counteract respiratory depression and provide other non-sedative pain relievers.

(5) Provide ventilatory support if necessary.

3.3. Sedation

(1) When Sedation Occurs

Identify the cause (differential diagnosis), such as cancer-related fatigue, brain lesions, concurrent use of other sedative medications, or other factors (dehydration, infection, hypoxia).

(2) If caused by opioids

- Reduce the dosage of the opioid.
- Consider administering caffeine.

(3) If sedation is severe

- Reassess the cause.
- Add other non-pharmacological pain relief methods to reduce opioid usage.
- Consider switching between different opioids.

3.4. Delirium/agitation

(1) When delirium/agitation occurs

- Identify and address possible causes (differential diagnosis), such as central nervous system lesions or the effects of other medications, and provide appropriate treatment.
- Consider using non-opioid analgesics to reduce opioid usage.
- Consider reducing the dosage or switching between opioids.

(2) If delirium/agitation persists, seek assistance from a psychiatrist.

3.5. Cognitive impairment

(1) Cognitive impairment rarely occurs in patients after two weeks of stable opioid dosage.

(2) This side effect may occur during initial dosing or dose escalation.

(3) Identify the cause and provide appropriate treatment (differential diagnosis).

3.6. Nausea and vomiting

(1) Prevention

- Nausea and vomiting are common side effects of opioids, usually occurring during the initial use (within one week) or with dose increases.
- Prophylactic use of antiemetics is recommended for patients who have previously experienced nausea and vomiting with opioid use.

(2) When nausea and vomiting occur

- Identify other possible causes (differential diagnosis), such as radiation therapy, chemotherapy, intestinal obstruction, or brain lesions.
- Administer antiemetic treatment.
- Administer corticosteroids.

(3) If Nausea and vomiting persist for more than one week

- Reassess the cause of nausea and vomiting.
- Consider adding other pain relief methods to reduce pain and decrease opioid usage.
- Consider switching between different opioids.

3.7. Itching

(1) When itching occurs

- Administer antihistamines for itching not caused by central nervous system administration.
- For itching caused by central nervous system administration of opioids, stop that route of administration and switch to a different route.

(2) If itching persists

- Consider switching to a different opioid.
- Administer a small dose of opioid antagonist intravenously, if necessary, to counteract the side effects of opioids.
- Add other non-opioid analgesics to assist in pain relief.

3.8. Urinary retention

In males with benign prostatic hyperplasia or tumors in the lower abdomen, reduce opioid dosage or use bladder sphincter relaxants. This side effect (urinary retention) usually occurs only in the initial week of opioid use and gradually decreases thereafter.

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Chapter 11

Rehabilitation Therapy

1. Introduction

Palliative/terminally ill patients often experience pain, fatigue, weakness, organ failure (such as heart or respiratory failure), nerve damage, and musculoskeletal issues. Rehabilitation therapy includes physical therapy, occupational therapy, psychological therapy, and speech/swallowing therapy. Based on the treatment goals and in conjunction with palliative care, a multidisciplinary team provides individualized rehabilitation to address both the physical and psychological needs of the patient. This approach aims to maintain or restore physical function, preserve mobility and independence, alleviate symptoms, enhance quality of life, and reduce the burden on families and caregivers. This chapter introduces the rehabilitation therapies offered in medical institutions.

2.Types of rehabilitation

Based on the patient's stage of illness, organ function, and treatment goals, rehabilitation is classified as follows:

2.1. Preventive rehabilitation: Initiated after the diagnosis of a life-threatening illness to prevent or mitigate disabilities that may arise from the disease or its treatment.

2.2. Restorative rehabilitation: Aims to promote the recovery of the patient's organ functions.

2.3. Supportive rehabilitation: Enhances self-care and mobility to improve functional abilities.

2.4. Palliative rehabilitation: For palliative patients, this focuses on alleviating symptoms (such as pain, numbness, swelling, and shortness of breath) and preventing complications (such as joint contractures and pressure sores) to maintain quality of life and reduce dependence.

3. Rehabilitation intensity

Rehabilitation intensity can be adjusted according to disease progression. Even in the terminal stages, rehabilitation therapy can be conducted at the patient's bedside.

4. Rehabilitation goals

4.1. Communicate with the patient and their family about the goals of rehabilitation therapy and jointly decide on an appropriate rehabilitation plan.

4.2. Focus on improving the patient's quality of life, functionality/independence, and psychosocial health, rather than merely extending survival time.

4.3. Measure objective outcomes, while also considering the mental and physical burden on healthcare providers and caregivers. Respect the patient's choices and allow for frequent interruptions in the rehabilitation plan.

5. Indications for initiating rehabilitation therapy

5.1. Frequent falls at home.

5.2. Cognitive function changes affecting daily life.

5.3. Pain or numbness that limits physical activity and function.

5.4. Interest in long-term guidance and training programs.

5.5. Worsening condition requiring hospitalization, accompanied by a decline in functional status.

5.6. Reports from caregivers or family members of increased caregiving burden.

6. Common rehabilitation needs for various diseases

6.1. Cancer

(1) Rehabilitation needs for advanced cancer patients commonly include: Pain, fatigue, dyspnea, prolonged bed rest, physical dysfunction, joint contractures or muscle atrophy, and sequelae from medication/surgical/radiation therapy (e.g., lymphedema, swallowing difficulties).

(2) Rehabilitation methods for managing cancer pain are divided into four categories:

- Pain modulation: Techniques like transcutaneous electrical stimulation, hot and cold therapy.
- Stabilizing or alleviating pain mechanisms: Includes postural positioning, vibration, counter-stimulation and desensitization techniques, manual lymphatic drainage and massage, proprioceptive neuromuscular facilitation techniques.
- Using physical therapy devices to relieve pain: Such as interferential current therapy, ultrasound, and laser therapy.
- Rehabilitation for musculoskeletal pain: Includes assistive devices, therapeutic exercises, and myofascial trigger point release techniques.

6.2. Chronic respiratory diseases

(1) Pulmonary rehabilitation can significantly improve dyspnea, enhance exercise endurance, reduce anxiety, and lower the rate of rehospitalization.

(2) Components of pulmonary rehabilitation include:

- Exercise training: Upper and lower limb endurance training, strength training, respiratory muscle training, relaxation techniques, breathing regulation techniques, postural drainage, and mucus clearance techniques.
- Education on related knowledge and techniques: Breathing exercises, speaking, breathing, and swallowing techniques, physical fitness adjustment, work simplification, and end-of-life education.
- Enhancement of psychological, spiritual, and social support: Coping strategies and stress management.

6.3. Heart failure

(1) Rehabilitative exercise can improve clinical symptoms and prognosis for heart failure patients, reduce anxiety and depression, and lower rates of rehospitalization and mortality.

(2) Personalized cardiac rehabilitation programs include: Supervised continuous and intermittent aerobic training, physical activity counseling, psychosocial support, weight control, and smoking cessation education.

(3) For patients with stable mild to moderate heart failure without severe arrhythmias or other exercise limitations, cardiac rehabilitation is an appropriate choice. There is insufficient evidence to show that cardiac rehabilitation benefits patients with severe heart failure.

6.4. Neurodegenerative diseases

These diseases are characterized by progressive and irreversible loss of neurological function, leading to a gradual loss of mobility and independence.

(1) Amyotrophic Lateral Sclerosis (ALS)

Gait and balance training, manual or electric wheelchair training, speech therapy, swallowing technique training, and dietary adjustments.

(2) Dementia

Rehabilitation therapy can improve the quality of life and physical activity functions of patients.

(3) Parkinson's disease

Rehabilitation aims to improve sleep quality and physical functions, including gait and balance.

6.5. Others

In elderly patients with organ failure, conditions may rapidly deteriorate and become difficult to manage. During consultations or hospitalizations, there may be only a short window of opportunity to provide rehabilitation services.

7. Underutilization of rehabilitation

7.1. Rehabilitation therapy can provide effective assistance for palliative/end-of-life patients.

7.2. However, in general, the utilization rate of rehabilitation among palliative patients is insufficient in both quality and quantity.

8. Risks of rehabilitation

Rehabilitation risks include exacerbation of pain due to procedures or exercises, fractures in patients with bone metastases, cardiovascular risks, and falls during the rehabilitation process.

9. Rehabilitation service venues

9.1. For palliative/end-of-life patients, rehabilitation services can be provided in various settings, including hospitals of all levels, rehabilitation clinics, skilled nursing facilities, hospice care facilities, and at home.

9.2. The intensity and scope of services may vary across different settings. Factors influencing the choice include disease type/stability, overall disease course, care goals, patient cognition, treatment tolerance, motivation, desires, and preferences.

10. Timing for terminating services

10.1. The patient's rehabilitation goals have been achieved.

10.2. The patient and/or their family refuse to continue receiving treatment services.

10.3. Physical or occupational therapy can no longer provide the required therapeutic services.

10.4. The patient is discharged from the hospital or inpatient facility.

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Chapter 12

Psychological, Spiritual, Social, and Emotional Support

1. Introduction

1.1. The challenges faced by terminally ill patients and their families

Terminally ill patients and their families face not only the challenges of incurable disease and the inevitability of death but also multi-dimensional suffering. This suffering encompasses physical (physiological), psychological (mental), spiritual, and social (family and economic) aspects, collectively referred to as "total suffering" (see Figure 1).

(1) The patient's experience and life struggles

When patients endure persistent and unrelieved pain, they often feel isolated and hopeless, sometimes developing suicidal thoughts or requesting euthanasia as an expression of their despair.

(2) World Health Organization's definition of palliative care

Palliative care is defined as:

- Assessing, preventing, and alleviating suffering: Addressing pain across the physical, psychological, spiritual, and social dimensions.
- Supporting patients and families: Providing aid to patients with life-threatening conditions and their families to help them navigate challenges.
- Enhancing quality of life: Delivering comprehensive care to ensure patients experience maximum comfort and dignity during their remaining time.

(3) The philosophy of holistic care

The care of terminally ill patients should adopt a holistic approach, addressing multiple dimensions of suffering. The goal is not only to relieve pain but also to help patients embrace each day with positivity, ensuring they live meaningfully and with dignity until the natural end of life.

Figure 1: Total suffering

1.2. Characteristics of the palliative care team: Uniqueness and multidisciplinary collaboration. The palliative care team is a specialized medical team distinct from general healthcare teams. Its characteristics include:

(1) Multidisciplinary collaboration

The team consists of members from diverse professional backgrounds, encompassing medical, psychological, social, and spiritual care domains.

(2) Core members

Social workers, psychologists, and chaplains (spiritual care providers) are central to the care team, offering psychological and spiritual support. For patients with psychiatric symptoms, psychiatric professionals join the team to provide supplemental care.

1.3. Scope of palliative care: comprehensive care for patients and families

Palliative care addresses not only the patient but also the entire family, beginning at the stage of disease diagnosis.

(1) Common issues faced by patients

Fatigue and pain are the most frequently encountered physical symptoms.

(2) Challenges for family caregivers

- Emotional tension and caregiving burdens.
- Uncertainty about the patient's health.
- Fear of facing a loved one's death.
- Changes in roles and lifestyle.
- Economic pressures.
- Differences in opinions and needs between patients and family members.

(3) Supportive role of the team

The team provides psychological, social, and spiritual support to both patients and caregivers, improving their quality of life.

1.4. Spiritual issues faced by terminally ill and end-of-life patients

(1) Seven common spiritual distresses

- Loss of self-esteem: Feeling a diminished sense of self-worth.
- Self-abandonment: Losing hope or giving up on oneself.
- Attachment: Difficulty letting go of life, loved ones, or unfinished matters.
- Fear of death: Anxiety over the unknowns of death.
- Unfulfilled wishes: Regret from unaccomplished goals or desires.
- Misunderstanding of moral or existential principles: Misconceptions about life's meaning and ultimate concerns.
- Other issues: Problems requiring the soothing and presence of chaplains or spiritual mentors.

(2) Key aspects of spiritual care

- Helping patients accept death: Support patients in confronting the ultimate challenge.
- Resolving spiritual distress: Alleviate existential and spiritual struggles.
- Guiding spiritual growth:
- Affirm the value of life.
- Assist in fulfilling unachieved wishes.

- Help patients perceive spiritual presence and seek mental growth within their limited lifespan.

1.5. Integration of holistic care and pain management

Effective pain relief requires the integration of support from three dimensions:

(1) Psychological support: Stabilize emotions and reduce mental burdens.

(2) Spiritual support: Help patients find inner peace and the meaning of life.

(3) Social support: Encourage participation from family, friends, and social resources.

These are closely related to and interact with the holistic care principles of palliative care. Only through multidimensional support can the best outcomes be achieved.

2. Challenges in pain management

Pain management is a core element of palliative care. However, many people associate pain solely with disease and overlook the influence of psychological, social, and spiritual factors, which can significantly affect treatment outcomes. Below are common influencing factors:

2.1. Family and social factors

(1) Family refusal or self-adjustment of medications

- Some family members may refuse to use pain medications, adjust dosages without consultation, or discontinue medications due to a fear of addictive drugs.

- Misconceptions about medication treatment: For example, believing that using pain medication signifies disease progression, misinterpreting disease advancement as treatment failure, and consequently losing confidence in medication.
- Cultural factors: Traditional beliefs that consider pain medications unnecessary or harmful.

(2) Solutions:

When such situations arise, seek assistance from the palliative care team, which can provide:

- Clear explanations of medication purposes: Clarify the effectiveness and safety of medications to dispel addiction fears.
- Evaluation of past medication experiences: Identify if inappropriate medication use has caused fear.
- Correction of misconceptions: Educate caregivers and families to address cognitive biases.
- Medication adjustment and side effect monitoring: Optimize medication regimens based on the patient's condition, reducing side effects and building trust.
- Psychological and cultural support: Address concerns stemming from cultural pressures or family beliefs to encourage adherence to proper medication plans.

2.2. Psychological and spiritual factors

Psychological and spiritual dimensions are crucial to the pain and quality of life of terminally ill patients. Common issues and strategies include:

(1) Anxiety

- Symptoms: Patients may experience anxiety or insomnia due to physical pain or psychological distress.
- Management: Improve physical symptoms: Alleviate discomfort to enhance natural sleep opportunities.
- Use of medications: Appropriately administer anti-anxiety or sleep medications to help maintain regular sleep, stabilize emotions, reduce physical exhaustion, and enhance well-being.

(2) Total suffering

Total suffering involves the comprehensive dissolution of body, mind, spirit, and social well-being as death approaches. It encompasses four interrelated dimensions:

- Physical pain: Such as widespread pain, breathing difficulties, and gastrointestinal discomfort.
- Psychological pain: Including anxiety and depression.
- Social pain: Such as financial stress and family problems.
- Spiritual pain: Seeking life's meaning, exploring the reality of death, and finding spiritual comfort.

The interplay of these dimensions amplifies the patient's suffering, necessitating holistic care to provide relief.

(3) Demoralization syndrome

- Symptoms:
  - ☆ Key features: Persistent hopelessness, helplessness, and a loss of meaning or purpose in life.

☆ Emotional distress in cancer patients: About half of emotionally distressed patients have depression, while the other half experience demoralization syndrome.

- Differences from depression:

☆ Depression: Patients feel emotionally numb and powerless toward everything.

☆ Demoralization syndrome: Patients may outwardly display emotional reactions, such as laughing at a joke, but internally feel life is meaningless.

- Diagnostic criteria:

☆ Based on U.S. and Australian guidelines, patients experiencing daily helplessness for a month can be diagnosed with demoralization syndrome.

☆ Suicide risk: Patients with demoralization syndrome have an even higher suicide rate than those with depression.

3. Approaches to psychological, social, and spiritual support

In palliative care, psychological, social, and spiritual support are indispensable components. Below are specific intervention methods:

3.1. Psychological/mental interventions

(1) Assisting in understanding the illness

Help patients and families comprehend the current state and progression of the illness, fostering accurate awareness.

(2) Crisis management

Support patients and families in dealing with unexpected situations and developing effective coping strategies.

(3) Enhancing resilience

Provide psychological support to strengthen patients' and families' ability to face challenges.

(4) Clarifying life values

Assist patients and families in reflecting on their values and life's meaning to provide direction and inner peace.

(5) Monitoring emotional responses

Continuously observe emotional states and provide timely emotional counseling and intervention.

(6) Planning for remaining time

Address patients' expectations for their remaining time, including treatment preferences, care settings, and daily arrangements. If discrepancies arise between the medical team's views and family expectations, facilitate a family meeting to reach a consensus.

3.2. Social support

(1) Referral to social resources

Evaluate the family's support system and financial situation, and assist with referrals to social resources or economic assistance.

(2) Emotional support

Help patients and families express emotions, resolve conflicts stemming from the disease journey, and promote family harmony.

(3) Spiritual care

Connect patients with religious or spiritual care providers to offer faith-based support during their final journey.

(4) Strengthening communication

Enhance communication between patients, families, and the medical team to foster a harmonious relationship.

(5) Fulfilling wishes

Assist patients in achieving unfulfilled wishes to help them feel a sense of completeness and comfort.

(6) Discharge planning

Provide information on home and long-term care options to help patients and families plan post-discharge care.

(7) Funeral assistance

Facilitate positive discussions about end-of-life arrangements, including burial preferences and legacy planning.

(8) Bereavement support

Offer continued support to families after the patient's passing, helping them cope with grief and loss while rebuilding their lives.

3.3. Spiritual support

Spiritual support is a critical aspect of palliative care, helping patients find strength, peace, and meaning. Specific approaches include:

(1) Encouraging life reflection

- Reviewing life: Guide patients in recounting significant life experiences.
- Identifying life's meaning: Help patients explore their purpose, values, and meaning, providing inner comfort and serenity.

(2) Addressing emotional issues

- Exploring guilt and blame: Assist patients in confronting regrets or self-reproach to alleviate emotional burdens.
- Promoting forgiveness and reconciliation: Help patients reconcile with themselves or others to achieve emotional release.

(3) Exploring sources of suffering

- Differentiating types of suffering: Determine whether suffering stems from current circumstances, long-term depression, guilt, or unresolved internal conflicts.
- Facing suffering: Provide guidance and support to help patients accept and address the root causes of their pain.

(4) Applying beliefs to the present

Using beliefs and philosophies: Encourage patients to draw on their life philosophies or beliefs to find inner strength.

(5) Respecting cultural and religious needs

Acknowledging patient needs: Respect cultural practices, dietary restrictions, religious customs, and key beliefs to ensure patients feel understood and supported.

(6) Conducting religious rituals

Supporting religious activities: Facilitate or assist with prayer, meditation, confessions, baptisms, or other faith-aligned practices to provide spiritual comfort and solace.

(7) Encouraging spiritual healing techniques

Using relaxation and creativity: Support patients in utilizing relaxation, visualization, music, and reading to ease inner tension and strengthen their spiritual resilience.

Note:

1. Explanation of spirituality: Everyone has innate goodness within (like an "angel"), though negative impulses (like a "devil") may occasionally surface. Spirituality is that innate goodness, and by practicing it, inner strength grows, bringing balance and joy to both mind and body.
2. Ways to practice spirituality: For example: Empathy: Show care for the struggles of others. Gratitude: Approach life and others with a thankful attitude. Selflessness and universal love: Enrich life's meaning through altruistic actions. Four expressions of life: express love, gratitude, apology, and farewell. Pursuit of truth, goodness, and beauty: Face life with a positive and sincere attitude. Active kindness: Begin with small acts of kindness in daily life, gradually building positive energy to give back to those who care about you and those you care for.

4. Distinguishing pain from suffering

Pain and suffering are distinct concepts. Suffering (or affliction) encompasses a more complex and multidimensional nature, posing profound threats and impacts on the physical, psychological, spiritual (existential), and social dimensions of an individual.

4.1. What is "total suffering"?

(1) Interwoven pain

Suffering is not merely physical discomfort; it is a multilayered experience of pain that intertwines the physical, psychological, spiritual, and social dimensions. For example, pain, illness, psychological stress, and negative emotions can all contribute to the source of suffering.

(2) The context of terminally ill patients

Terminally ill patients face not only physical discomfort but also the complexities of societal and cultural contexts and spiritual challenges, such as: Helplessness caused by physical frailty. The search for existential meaning. Economic burdens and family relationship pressures.

(3) The need for understanding and companionship

Suffering is not a problem that demands immediate "resolution" but rather one that requires understanding and companionship to alleviate its pressure and harm to the patient.

(4) Incurable diseases, treatable suffering

When diseases can no longer be cured, relieving suffering becomes the primary goal of medical care.

4.2. The need for holistic care

(1) Multidimensional impacts

Terminally ill patients face physical, psychological, social, and spiritual challenges, with individual responses varying according to their unique backgrounds and contexts.

(2) Unified holistic needs

While each patient's care needs may differ, the core principle of holistic care remains consistent: providing comprehensive support on all levels to alleviate the patient's suffering.

5. Conclusion

When patients face disease progression, uncontrolled symptoms, or feelings of defeat and meaninglessness, their suffering is often compounded by disrupted relationships with others, insufficient support from loved ones, economic pressures, and the perceived burden on their families. These interconnected issues exacerbate the anxiety and pain of terminally ill patients.

5.1. Careful observation and understanding

Caregivers must attentively observe the meaning behind a patient's behavior and understand the sources of their suffering to provide appropriate support.

5.2. Tailored care plans

(1) Individualized care: Develop personalized care plans based on the specific needs of the patient.

(2) Multidimensional support: Offer timely care and attention across psychological, social, and spiritual dimensions.

5.3. Dual goals of pain management and suffering relief

(1) Optimal pain control: Address not only physical pain but also psychological and spiritual distress.

(2) Relief of total suffering: Employ holistic care to help patients find peace and comfort during the final stages of life.

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Chapter 13

Emergency Palliative Care and Pain Management

1. Introduction

1.1. Terminally ill patients are often brought to the emergency room due to urgent situations, and the quality of care they receive in the emergency department significantly impacts their disease progression, patient/family satisfaction, and medical expenses.

1.2. Terminally ill patients typically have multiple and complex issues requiring interdisciplinary teamwork, particularly collaboration with palliative care teams, to provide proper and continuous care and to reduce the burden on family caregivers.

1.3. This chapter explains the actions taken by the medical team regarding emergency palliative and pain management, providing the public with necessary information.

2. Definitions

2.1. Palliative care: Refers to the alleviating and supportive medical care provided to reduce or eliminate the physical, psychological, social and spiritual suffering of terminally ill patients to enhance their quality of life.

2.2. Terminally ill patient: Refers to a patient suffering from a severe illness or injury that is deemed incurable by a physician, with medical evidence indicating that the disease will inevitably progress to death in the near future.

2.3. Cardiopulmonary Resuscitation (CPR): Refers to the standard emergency procedures or other urgent medical interventions administered to terminal, dying, or unresponsive patients, including endotracheal intubation, external cardiac compression, emergency drug injections, cardiac defibrillation, cardiac pacing, and artificial respiration.

2.4. Life-sustaining treatment: Refers to medical measures used to maintain the vital signs of terminal patients, which do not have a curative effect but only prolong the dying process.

3. Emergency assessment and management principles

3.1. Terminally ill patients already receiving palliative care may still come to the emergency department due to urgent situations. When these patients arrive at the emergency department, the following assessment and management principles are commonly used by healthcare providers:

(1) Treat symptoms of distress: Provide patient-centered physical and emotional support to both the patient and their family.

(2) Notify the original palliative care team: Inform the team that the patient is in the emergency department and confirm whether cardiopulmonary resuscitation (CPR) and life-sustaining treatments are needed if the condition worsens.

(3) Adhere to the patient's pre-determined care goals: Discuss with the original palliative care team whether diagnostic tests and related treatments are necessary.

(4) Assess pain levels: Evaluate the patient's pain intensity and current pain medications, providing adequate analgesics and appropriate dosages.

(5) Avoid invasive treatments: Unless agreed upon by the original palliative care team and family, avoid invasive treatments, including IV lines. Dehydration due to cessation of eating and drinking is a natural part of the dying process.

(6) Provide a private space for imminent death: If the patient is expected to die soon, offer a private space for the family to accompany the patient in their

final moments. Although emergency space may be limited, consider designating a quiet and private area for dying patients and their families to say goodbye. This space can be used flexibly, accommodating other patients when not needed for end-of-life care.

(7) Administer medications for agitation and anxiety: Provide medications to relieve agitation and anxiety. Oxygen can be provided as needed without restriction.

(8) Discuss CPR and life-sustaining treatment for new patients: For patients not previously receiving palliative care but judged to be in the terminal stage of illness and deteriorating, discuss with the patient or family whether to proceed with CPR and life-sustaining treatment. If the patient or family cannot decide immediately, consider a "time-limited trial" of treatment. A time-limited trial involves agreeing to administer a certain treatment for a specified period. If the patient improves within this time, continue treatment; if not, discontinue treatment and shift the focus to palliative care.

4. Management of dyspnea

4.1. Dyspnea in terminally ill patients often causes anxiety and stress for both the patient and caregivers. During assessment, it is crucial first to confirm the patient's care goals and then look for immediately treatable reversible causes such as hypoxia, fluid overload, pain, and anemia, while avoiding excessive diagnostic tests.

4.2. Opioids are the first choice for alleviating dyspnea as they can break the cycle of anxiety caused by breathing difficulties. Additionally, providing oxygen, elevating the head of the bed, and using a fan to blow cool air on the patient's face may also be helpful.

4.3. If the cause of dyspnea is reversible/treatable, consider appropriate treatments to alleviate the symptoms. For example, pleural effusion can be relieved with thoracentesis.

5. Management of pain

Pain is a very common symptom at the end of life, especially in terminal cancer patients. These patients often experience acute pain crises (severe pain) and may have developed tolerance to high doses of opioids used routinely. Despite this, opioids remain the first choice for managing severe pain in terminally ill patients. Healthcare providers will administer appropriate medications based on the patient's condition.

6. Management of fever and infection

6.1. Infections are common in terminally ill patients, and the approach to evaluation and management depends on the patient's care goals and prognosis.

6.2. If the goal is to improve quality of life, it is recommended to treat with empirical oral antibiotics. Decisions regarding blood cultures, IV fluids or antibiotics, and laboratory tests should be made on a case-by-case basis after discussion with the patient and family.

7. Interdisciplinary team care

7.1. There is no fixed model for providing palliative care in the emergency department; it depends on the resources and goals of each hospital.

7.2. Early consultation with the palliative care team in the emergency department can help improve the quality of life at the end of life for patients, including reducing hospital stays and emergency visits, and helping families cope with the loss of a loved one.

7.3. For patients not yet receiving palliative care, emergency physicians can play an important role in initiating palliative care.

8. Summary

8.1. Terminally ill patients are frequently encountered in the emergency department.

8.2. Providing palliative care in the emergency department can reduce suffering for both patients and families, making subsequent treatment plans smoother.

8.3. Emergency physicians need to understand the expectations of patients and families, manage symptoms, and provide appropriate referrals.

8.4. Providing palliative care in the emergency department requires collaboration among an interdisciplinary team, especially close cooperation with the palliative care team, to provide proper and continuous care for the patient.

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Chapter 14

Palliative Care and Pain Management for the Elderly

1. Introduction

1.1. Ideal palliative care for the elderly provides comprehensive care that meets the needs and expectations of the elderly as they approach the end of their lives.

1.2. The primary focuses of elderly palliative care include symptom management, restoration of physical function, enhancement of quality of life, and achieving a good end of life (a dignified death). Appropriate care should be available whether the elderly are hospitalized, in nursing facilities, or at home.

1.3. Palliative care for the elderly encompasses a wide range of services, including:

   (1) Care for terminally ill patients with cancer and non-cancer conditions.

   (2) Transition from aging to physical dependency.

   (3) Continuum of care from hospital to community to home.

   (4) Support from gradual physical decline to end-of-life.

1.4. Palliative care for the elderly differs from that for younger patients in several ways:

   (1) Elderly patients often have long-standing chronic diseases and require assistance due to cognitive issues and multiple comorbidities, necessitating long-term care and multifaceted support.

   (2) Palliative care for the elderly not only addresses end-stage disease or cancer symptoms but also focuses on improving physical function, cognitive issues, reducing frailty, and alleviating caregiver burden.

1.5. Elderly palliative care can be divided into two models:

   (1) Disease-oriented palliative care.

   (2) Frailty-oriented palliative care.

1.6. This model involves several steps:

   (1) Initially aiming for cure upon disease onset.

   (2) Transitioning to symptom relief and management when cure is no longer possible.

(3) As physical function declines, care plans are developed based on joint decisions between the physician and the patient. This stage includes physical, psychological, social, cultural, and economic support.

1.7. Frailty-oriented palliative care:

(1) Focusing on the psychological, social, cultural, and economic needs of the patient. It is patient-centered, encouraging patient involvement in their own medical decisions. Emphasizing the maintenance of remaining abilities rather than solely focusing on lost capabilities and medical issues, thereby enhancing psychological comfort and well-being.

(2) Using assessment tools to evaluate the palliative care needs of frail elderly patients, understanding their needs, and discussing their life values and adjusting treatment methods accordingly.

2. Pain management in palliative care for the elderly

2.1. Pain in the elderly

(1) In the community: Approximately 25% to 56% of elderly individuals in the community experience pain. The most common types of pain are back pain and joint pain.

(2) In nursing homes: The proportion of elderly individuals experiencing pain in nursing homes can be as high as 45% to 80%. Besides pain, these individuals may also face issues such as depression, reduced

participation in social activities, poor sleep, increased risk of falls, side effects from medications, slower recovery, and more frequent doctor visits.

(3) Causes of pain:

Pain is usually related to the severity of illnesses or injuries. Common causes include:

- Musculoskeletal issues: Such as back pain and arthritis.
- Neuropathic pain: This may result from conditions like diabetes, post-herpetic neuralgia, post-surgery, or other nerve injuries.
- Nighttime leg pain: Such as cramps or restless legs syndrome.
- Cancer pain: Especially prevalent at the end of life.

(4) Assessment and impact of pain:

- Multiple conditions: Elderly individuals often suffer from multiple ailments, making pain assessment and treatment challenging. The risk of medication side effects or complications from treatment is also higher than in the general adult population.
- Social impact: At the end of life, elderly individuals heavily rely on family and caregivers. The stress and attitudes of caregivers significantly affect the effectiveness of pain management.

2.2. How aging affects pain perception

(1) It is currently uncertain in medical science whether age alters pain perception. However, elderly individuals often have other sensory issues that prevent them from accurately expressing pain.

(2) Cognitive issues: Problems with brain function, sensory nerve damage, and vision and hearing impairments in elderly individuals can make expressing and communicating about pain more difficult.

(3) Stoicism and fear: Some elderly individuals may be more stoic or reluctant to undergo examinations or treatments due to fear of pain, complicating pain assessment and management.

3. Pain assessment

3.1. Before starting pain treatment, it is essential to understand the patient's medical condition, cognitive and physical functional status, treatment goals, and expectations. Additionally, social resources and family support are crucial.

3.2. Pain assessment in patients with cognitive impairment

(1) Primary caregivers are usually able to observe the patient's pain or related abnormalities, including general behavior, medication usage, and factors that increase or decrease pain. However, family members and caregivers may have limitations in interpreting the causes or severity of these behaviors and events, and their judgments on pain severity may not always be accurate.

(2) Patients with mild to moderate cognitive impairment can be assessed using standard pain scales.

(3) For patients with severe cognitive impairment, deep coma, or locked-in syndrome, pain assessment can be conducted by observing their facial expressions and body language.

Note: Locked-in syndrome refers to a condition where the patient is fully conscious but completely paralyzed except for some facial and eye movements. This condition often results from a stroke affecting the brainstem. Special communication aids and assistive devices can facilitate interaction between the patient and the external world.

4. Basic principles of pain management in palliative care for the elderly

4.1. Effective pain management relies on regular standardized assessments, rational use of pharmacological and non-pharmacological treatments, and proper handling of opioid side effects.

4.2. The World Health Organization proposed a three-step model for cancer pain treatment in 1986, which remains a fundamental approach for treating cancer pain and is commonly used for palliative care or end-of-life pain management.

(1) Mild pain: Use non-opioid medications like acetaminophen, aspirin, or non-steroidal anti-inflammatory drugs (NSAIDs). Other adjuvant medications can be added if necessary.

(2) Mild to moderate pain: Use weak opioids, adding medications for mild pain if needed.

(3) Moderate to severe pain: Use strong opioids like morphine, adding medications for mild to moderate pain if needed.

Note: For palliative or terminal pain management, appropriate steps and analgesics can be chosen directly based on pain severity, especially for acute pain, without needing to progress step-by-step.

4.3. For mild pain, acetaminophen is considered the first choice. NSAIDs should be used cautiously and only in patients with good renal function and no history of peptic ulcers or gastrointestinal bleeding. For moderate pain, consider weak opioids or low doses of strong opioids.

4.4. Start with low doses of analgesics and gradually increase until effective pain relief is achieved with minimal side effects.

4.5. Neuropathic pain (e.g., caused by diabetes, post-herpetic neuralgia, post-stroke, or peripheral nerve damage) is often challenging to treat. Multidisciplinary collaboration is needed. Anticonvulsants may be considered, but be mindful of side effects like dizziness and unsteady gait. Topical anesthetics can be applied to affected skin areas. Antidepressants should be used cautiously due to side effects and are not recommended as a first choice. Opioids are generally not effective and are not recommended as a first choice for these conditions.

4.6. Most side effects of opioids develop tolerance over time (i.e., the side effects become less noticeable), but constipation does not. For example, respiratory depression may develop tolerance within 48 to 72 hours, nausea within a few days to a week, and cognitive side effects (e.g., sedation and confusion) within 5 to 14 days.

4.7. Patients treated with opioids, even for just a few days, may develop dependence. Abrupt discontinuation or a significant dose reduction can lead to withdrawal symptoms (physical discomfort). Gradual tapering under medical supervision is advised. The risk of addiction is very low (less than 1%) in patients without a history of substance abuse. In life-threatening or terminal conditions, appropriate use of opioids should not be hindered by concerns about addiction.

4.8. For frail elderly patients, regular assessments and documentation of the treatment plan for deteriorating conditions or acute pain crises are essential.

4.9. For frail elderly patients expected to die within a week, regular pain assessments should be conducted and documented to ensure effective pain management at the end of life.

5. Acute pain management

5.1. The most important aspect of treating acute pain is to identify and address the underlying cause of the pain. Rapid-acting analgesics can be used in the short term, along with various non-pharmacological treatment methods.

5.2. The selection of analgesics and non-pharmacological treatments depends on the severity of the pain, available equipment, professional personnel, the possibility of removing the cause of the pain, and individual differences.

5.3. Mild pain is usually managed with non-opioid analgesics combined with physical therapy or cognitive-behavioral therapy.

5.4. Moderate pain typically requires weak opioids or low doses of strong opioids, often combined with acetaminophen.

5.5. Severe pain usually necessitates the use of strong opioids. For severe trauma or postoperative pain, intermittent intravenous injection, continuous intravenous infusion, or intrathecal administration can provide rapid and sustained pain relief.

5.6. Pain treatment should not be stopped even during diagnostic procedures. Pain management rarely interferes with the diagnostic process and helps the patient cooperate better when comfortable.

6. Chronic pain management

6.1. Treating chronic pain typically requires a combination of pharmacological and non-pharmacological methods. Although analgesics are the most common treatment, using cognitive-behavioral therapy and other non-pharmacological treatments can enhance pain relief and reduce the side effects from excessive use of analgesics.

6.2. Chronic pain management often involves regular pain assessments and adjusting treatment plans as needed. This approach requires collaboration among physicians, nurses, and other therapists.

6.3. Chronic pain is generally more challenging to alleviate than acute pain. Discussing realistic expectations for pain relief with the patient, along with potential treatment options, goals, and the pros and cons of each choice, is essential. When starting new medications, regularly review the dosage, administration method, efficacy, and side effects, and gradually discontinue ineffective drugs.

6.4. Economic factors should be considered during assessment and treatment, weighing the benefits and drawbacks.

6.5. Involving caregivers in learning about pain assessment and recording, as well as seeking community medical resources, can enhance treatment adherence and maintain treatment effectiveness.

7. Pharmacological treatment (including acute and chronic pain)

7.1. Principles of medication use

(1) All patients whose daily functioning or quality of life is affected by pain are suitable candidates for pain medication.

(2) Proper use of pain medications is safe and effective for the elderly, but it is essential to balance the benefits and risks. The elderly have significant individual differences, such as organ function decline and comorbidities, requiring tailored medication adjustments.

(3) Most pain medications do not require dose adjustments based on age alone. However, treatment should start with low doses and regularly reassess and adjust to achieve optimal pain relief with minimal side effects.

7.2. Routes of administration

(1) Some medications can be administered through multiple routes, such as subcutaneous injection, intravenous injection, transdermal application (patch), sublingual administration, or rectal administration. The least invasive route should be chosen whenever possible.

(2) Oral administration is the preferred route because it is convenient and provides relatively stable blood drug levels. Most oral pain medications begin to take effect within 30 minutes to 2 hours.

(3) Intravenous injection provides the fastest relief but requires more frequent monitoring.

(4) Intramuscular injections, although commonly used, have less stable absorption compared to oral routes and are more invasive, requiring repeated administration, making them less convenient and comfortable.

(5) Transdermal, rectal, and sublingual routes are suitable for patients with swallowing difficulties.

7.3. Timing of administration

(1) For acute pain, use fast-acting medications for short-term treatment.

(2) For chronic pain, long-acting pain medications should be used as a principle. Additionally, fast-acting medications can be used to treat breakthrough pain, including:

- Unpredictable breakthrough pain.
- Predictable pain related to physical activity or treatments.
- Paroxysmal and difficult-to-predict neuropathic pain.

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Chapter 15

Pediatric Palliative Care and Pain Management

1. Introduction

According to the World Health Organization (WHO) database, malignancies and HIV/AIDS are the most common conditions requiring palliative care among children and adolescents worldwide. Other conditions include progressively deteriorating congenital or genetic diseases, trauma, and prematurity. Infants, children, and adolescents who receive palliative care often face issues with symptom assessment and medication under-treatment due to their developmental stages and communication abilities. Pediatric palliative care should not be seen as merely scaled-down adult care; it is distinct due to children's unique physiological, developmental, social, psychological, spiritual, and relational needs. However, because pediatric mortality is relatively low, accumulating sufficient and proficient experience is challenging, leading to many issues being overlooked.

1.1. Characteristics of pediatric palliative care

(1) Children are in a constant state of growth both physically and psychologically. For children, school life and peer interactions are crucial parts of their lives, which must be considered in treatment and care plans. Children who coexist with illness for a long time often mature faster than their peers, with a deeper understanding of their health care plans, perspectives on life, and understanding of death.

(2) In pediatric palliative care, parents or primary caregivers play a vital communication role. They are significant figures in a child's development and are crucial in making end-of-life medical decisions. However, ethically, children's rights to express their wishes must be respected, and parents or proxies should not make decisions regarding life-sustaining treatments without considering the child's voice.

(3) Generally, people do not associate death with children. Although childhood mortality is low, having a critically ill or terminally ill child significantly impacts the family dynamics. Therefore, it is essential to assist parents or caregivers and address the needs of other family members, particularly the siblings of the sick child.

(4) Statistics show that the leading causes of death in infants are perinatal conditions, congenital anomalies, and accidental injuries. For children and adolescents, the leading causes of death are accidental injuries, malignancies, congenital anomalies, and heart diseases. For young adults, the leading causes are accidental injuries, malignancies, and heart diseases.

(5) Pediatric dosing should be based on body weight, often requiring liquid formulations for easier swallowing. If liquid forms are unavailable, tablets may need to be crushed, mixed with food, or dissolved in liquids. Pediatric pharmacokinetics differ from adults, and there is often a lack of efficacy and safety data for many drugs. Physicians prescribing for terminally ill children must carefully judge drug safety and confidently administer medications.

(6) Reducing children's fear and providing a medical environment that includes play and education are essential practices recognized internationally for supporting children's rights.

1.2. The five most common symptoms in children and adolescents receiving palliative care are fatigue and weakness, pain, nausea and weight loss, delirium and agitation, and dyspnea. Pain and dyspnea management often involve opioid medications, highlighting the importance of understanding, assessing, and using opioids in pediatric palliative care.

1.3. Other common symptoms include eating difficulties, constipation, diarrhea, mucosal ulcers, pruritus, infections, bleeding, fatigue, depression, and anxiety.

1.4. Given the developmental and compliance issues related to swallowing, careful attention must be paid to the route of administration. Ensure that medications are administered and absorbed effectively, using oral (including liquid formulations), mucosal (e.g., oral mucosa, rectal), transdermal, subcutaneous, and intravenous routes as needed.

1.5. As pediatric palliative care continues to develop, attitudes towards opioid use have shifted from cautious avoidance to ensuring appropriate use with careful evaluation.

1.6. In pediatric palliative care, symptom relief is crucial but often insufficient. Inadequate symptom relief can cause significant suffering, loneliness, and fear, severely impacting interpersonal relationships and quality of life. In addition to medications, palliative chemotherapy and radiation therapy can treat symptoms caused by tumors. Behavioral techniques such as deep breathing, relaxation, biofeedback, massage, physical therapy, heat and cold therapy, play, acupuncture, and expressive techniques such as art, music, drama, imagination, or hypnosis can also help alleviate some symptoms.

2. Recommendations for medication use in pediatric palliative care for pain and other symptoms

2.1. Pain management

(1) Between 60% to 90% of children receiving palliative care require opioid medications. Morphine, with extensive evidence and guideline support, is essential for effective pain relief in children and adolescents in palliative care. Accurate pain assessment is necessary before treatment, and for children who cannot express themselves verbally, the medical team will use facial expressions and body movement assessment tools.

- Opioids (especially morphine) are crucial for relieving severe pain in children. Dosages can be adjusted as needed. If side effects like nausea, vomiting, respiratory depression, drowsiness, constipation, hallucinations, nightmares, or difficulty urinating occur, the medical team should diagnose and manage these actively.

- Patient-controlled analgesia (PCA) devices can be used for children aged 5 and older.
- Alternatives to morphine, such as transdermal fentanyl patches, can be used for children aged 2 and older.

(2) These can be used as adjuvants in managing chronic pain in children.

(3) Widely used for musculoskeletal pain.

(4) Effective for reducing edema around tumors or lowering intracranial pressure.

2.2. Dyspnea (breathlessness)

(1) While there is less extensive research on its use in children compared to adults, high-quality evidence and expert consensus support using morphine to relieve dyspnea in children receiving palliative care. Administration can be oral, sublingual, or rectal.

(2) Often, anxiety accompanies dyspnea, and anxiolytics can be used as adjunct therapy when necessary.

(3) Injectable sedatives, supported by safety evidence, can be used for refractory dyspnea when oral medication is not an option.

2.3. Agitation

(1) Use language the child understands to comfort and soothe them, providing a familiar environment and caregivers. First, evaluate and address any underlying discomfort causing the agitation, then use appropriate sedatives as evaluated by the medical team.

(2) For managing psychiatric symptoms like hallucinations, antipsychotics can be administered orally, sublingually, or rectally.

2.4. Nausea/vomiting

Maintaining oral hygiene and a pleasant mouth odor is crucial for children with nausea/vomiting. Offer palatable food in small, appropriate amounts, monitor for dehydration or electrolyte imbalance, and correct these issues as needed. If necessary, the medical team can provide appropriate medications to alleviate these symptoms.

3. Psychosocial and spiritual issues in pediatric palliative care

3.1. Stages of death awareness and preparation

(1) Children under two years old are unable to understand death. At this stage, providing ample physical comfort and a sense of security through contact is essential. Children can comprehend that death and life are opposing concepts, but they might view death as reversible. During this stage, managing separation anxiety is crucial. Children understand that death is irreversible and can happen to themselves and their loved ones. They need help facing abandonment fears, maintaining interpersonal connections, and developing self-control. Adolescents comprehend that death signifies an end. It is important to allow them to express anger and disappointment and support them in engaging with their peer groups, fostering independence, and maintaining privacy.

(2) For school-aged children, continuing education and maintaining contact with peers are significant. They sometimes need to engage in purposeful activities, even if briefly, to sustain their confidence and sense of value. This involvement reassures them that parents and teachers still see them as capable individuals, enhancing self-affirmation.

(3) Helping children face death can include encouraging them to express their thoughts at appropriate times in their preferred ways. Assist them in conveying their concerns, love, and gratitude to parents and friends through photos, recordings, or drawings to help everyone navigate the process together.

3.2. Grief support

(1) Professional psychological and spiritual personnel and volunteer support teams can intervene to guide and support when necessary. It is essential to consider the child's developmental stage within the family and the family's cultural context, both internal and external.

(2) For perinatal palliative care, such as cases of severe congenital abnormalities detected during pregnancy, stillbirths, neonatal injuries, or extremely low birth weight preterm infants, the palliative care team needs to develop an integrated model. This model should address the ethical principles and the best interests of the fetus/newborn and the family, considering the fetus or sick infant's lack of decision-making ability. Providing necessary support to the parents during pregnancy and the neonatal stage is crucial, and decisions regarding life-sustaining treatment require cross-team discussion and review.

3.3. Advance care planning

Children often face illnesses with unpredictable courses (e.g., congenital abnormalities and rare diseases), making it challenging to estimate survival times. For children, distinguishing between curative and supportive treatments is often difficult (e.g., non-invasive ventilator support). Joint advance care planning discussions help the sick child and family understand the overall situation they might face, provide time for reflection, and allow the child to participate in their treatment and care. These discussions emphasize the importance of understanding the purpose and goals behind choosing or not choosing certain life-sustaining treatments, focusing on the desired life situation and quality of life.

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Chapter 16

Palliative Care for Postherpetic Neuralgia in Palliative Patients

1. Introduction

1.1. Herpes zoster, commonly known as shingles, is a prevalent infectious disease among middle-aged and elderly individuals, with a rising incidence rate. Research indicates that since the 1940s, the incidence has increased more than fourfold. The lifetime risk of contracting herpes zoster is approximately one in three, meaning one-third of people will develop it once in their lifetime. The primary risk factors for herpes zoster are older age and compromised immune function. In Taiwan, the incidence of herpes zoster in cancer patients in palliative care units is more than 20 times higher than in the general population. Postherpetic neuralgia is the most common complication of herpes zoster.

1.2. In the United States and Taiwan, two vaccines are approved and recommended for preventing herpes zoster and postherpetic neuralgia: a live attenuated vaccine and an inactivated recombinant vaccine. The live attenuated vaccine is contraindicated in immunocompromised individuals, while the inactivated recombinant vaccine can be used in adults with immune deficiencies or those who are immunosuppressed to prevent herpes zoster and its related complications.

2. Clinical manifestations of herpes zoster and postherpetic neuralgia

2.1. Herpes zoster, also known as "skin snake" or "flying snake" (in Taiwanese dialect), manifests primarily as a painful condition accompanied by a string of red rashes and blisters on the skin, resembling a snake coiling around the body.

2.2. The diagnosis of herpes zoster is primarily based on clinical symptoms, which include:

(1) Prodrome: Presence of stabbing pain or abnormal sensations (though this may not always occur).

(2) Dermatomal distribution: The rash follows a dermatomal pattern.

(3) Blisters and rash: Clusters of small blisters or papules followed by red rashes.

(4) Multiple lesions: Several lesions appear within the same dermatome.

(5) Pain: The rash is often accompanied by pain or tenderness.

2.3. After the skin lesions from herpes zoster heal, the affected area may continue to experience pain for more than three months, known as postherpetic neuralgia.

3. Pathogenesis of herpes zoster and postherpetic neuralgia

3.1. Herpes zoster, commonly known as shingles, is a painful neurocutaneous infection. When a person is first infected with the varicella-zoster virus (VZV), it causes chickenpox. After recovery from chickenpox, the virus remains dormant in the body, residing in the dorsal root ganglia or sensory neurons of the central nervous system. When this virus reactivates or replicates and spreads along the dermatomes, it causes herpes zoster. This reactivation often occurs years or even decades after the initial chickenpox infection. Therefore, people who have never had chickenpox or have not been vaccinated against it will not develop herpes zoster (Note: the chickenpox vaccine is a live attenuated vaccine).

3.2. Anyone who has been naturally infected with the wild-type VZV or has received the chickenpox vaccine can potentially develop herpes zoster due to reactivation of the virus in the body. However, compared to those naturally infected with the wild-type VZV, individuals vaccinated against chickenpox have a lower risk of VZV reactivation.

3.3. The pain from postherpetic neuralgia (PHN) is highly variable, including both spontaneous and evoked pain. Spontaneous pain may manifest as stabbing, burning, throbbing, electric shock-like, tearing pain, burning sensation, cold, numbness, or itching. Evoked pain includes allodynia (pain from stimuli that do not usually provoke pain), hyperalgesia (increased sensitivity to pain), and dysesthesia (abnormal sensations in the absence of stimuli). Patients may experience multiple forms of these abnormal sensations simultaneously.

4. Incidence of herpes zoster and postherpetic neuralgia

4.1. The primary risk factor for developing herpes zoster in the general population is advanced age, typically occurring in individuals over 50 years old. Approximately 60% of cases occur in women. Other risk factors include HIV infection, cancer, organ transplantation, use of immunosuppressive drugs, and other diseases that lead to decreased cellular immunity. In Taiwan, the incidence of herpes zoster increases with age, with two-thirds of cases occurring in patients over 40 years old.

4.2. In palliative care units, the incidence of herpes zoster in cancer patients is significantly higher (106 per 1,000 person, per year) compared to the general population in Taiwan (5 per 1,000 person, per year). This increased incidence is observed in both men and women, especially those over 60 years old.

4.3. Postherpetic neuralgia can persist for 30 days to over six months after the rash from herpes zoster heals, with pain eventually subsiding in most cases. In Taiwan, approximately 8.6% of herpes zoster patients develop PHN, with an incidence rate of 0.4 per 1,000 person, per year. Risk factors for PHN include older age, moderate to severe rash, moderate to severe acute pain during the rash, and ocular involvement. Studies also indicate that patients with herpes zoster and PHN often have deficiencies in micronutrients such as vitamins C, D, B12, zinc, and calcium, which are also risk factors for the disease.

5. Contagiousness of herpes zoster and daily precautions

5.1. Individuals who have never had chickenpox can contract the varicella-zoster virus (VZV) through airborne transmission (droplets) from a person with herpes zoster, although the incidence of respiratory symptoms in herpes zoster patients is low. It is recommended that patients wear masks to protect those living with them. Direct contact with the fluid from blisters or sores can also transmit the virus, leading to chickenpox. Close conversations, sharing utensils, and contact with the patient's clothing or towels all pose a risk of transmission. However, the contagiousness of herpes zoster is lower than that of chickenpox. Within the same household, the transmission rate for chickenpox is about 80-90%, while for herpes zoster, it is about 15%.

5.2. Adults who contract the VZV tend to have more severe symptoms than those who contracted it during childhood, so it is crucial to avoid exposure to the virus. Pregnant women, in particular, should avoid contact with individuals with herpes zoster, as the infection can be transmitted to the fetus, potentially causing low birth weight and eye or brain conditions. If someone in the household has herpes zoster, the patient should dine separately, avoid sharing baths, and not use the same personal hygiene items (e.g., towels, toothbrushes). Areas frequently touched by the patient, such as doorknobs and bedsheets, should be isolated or disinfected.

5.3. If diagnosed with herpes zoster, prompt treatment and adequate rest are essential to help the immune system recover and prevent the spread of the virus.

6. Prevention of herpes zoster and postherpetic neuralgia

6.1. There are currently two vaccines approved and recommended in the United States and Taiwan for the prevention of herpes zoster and its complications: the live attenuated zoster vaccine (Zoster Vaccine LIVE, ZVL; brand name Zostavax) and the recombinant zoster vaccine (Recombinant Zoster Vaccine, RZV; brand name Shingrix).

6.2. Live attenuated zoster vaccine: This vaccine is over 14 times more potent than the varicella vaccine, enhancing cellular immunity and reducing the risk of illness due to viral reactivation. Although its effectiveness in preventing the disease decreases with age, it can reduce the risk of developing chronic neuralgia. Live attenuated vaccines like ZVL are contraindicated for patients with compromised immune systems.

6.3. Shingrix, the recombinant zoster vaccine, requires two intramuscular injections, spaced 2 to 6 months apart. Common side effects after vaccination include muscle pain (most common), fatigue, headache, fever, and gastrointestinal discomfort, with an incidence rate of about 11%. These symptoms usually resolve within one to three days after vaccination. In July 2021, the U.S. Food and Drug Administration expanded the indications for RZV to include adults with immunodeficiency or immunosuppression.

7. Treatment of herpes zoster and postherpetic neuralgia

7.1. Managing the acute phase of herpes zoster (including pain relief) can prevent the initiation of chronic pain mechanisms, thereby reducing the risk of postherpetic neuralgia (PHN). Early treatment is recommended to prevent complications; appropriate antiviral treatment within three days of rash onset can effectively control the spread of herpes zoster and reduce the incidence of PHN.

7.2. Treatment typically includes antiviral medications to reduce the viral load, anti-inflammatory drugs to alleviate inflammation, and a combination of painkillers and antidepressants to relieve pain symptoms. Sometimes, appropriate use of corticosteroids can also reduce the incidence of PHN.

7.3. In Taiwan, acyclovir, famciclovir, and valacyclovir are available for oral administration. Intravenous acyclovir is also available. If the patient has a resistant virus strain, intravenous foscarnet can be administered, though its safety needs further evaluation.

7.4. Pain management strategies vary depending on the nature of the pain and may include:

(1) Tricyclic antidepressants

(2) Anticonvulsants

(3) Local anesthetics or analgesic creams

(4) Transcutaneous electrical nerve stimulation (TENS)

(5) Nerve blocks

(6) Opioids

(7) Micronutrient supplementation

7.5. Micronutrient supplementation: Recent studies indicate that low levels of micronutrients (e.g., vitamins C, D, B12, zinc) are risk factors for herpes zoster and PHN. Deficiencies in these nutrients may affect the clinical course, efficacy of drug treatments, and incidence of complications. Molecular studies show that nutrients like vitamins C and D and zinc have antiviral and neuronal excitability-regulating effects. Clinical studies have found that supplementing these nutrients can provide pain relief, such as intravenous vitamin C or zinc, oral vitamin D, or intramuscular vitamin B12 injections, which can alleviate pain in some PHN patients and be used as adjuncts to analgesics.

7.6. Despite the availability of various treatment methods, the efficacy of PHN treatments varies among individuals. Some patients achieve complete recovery, while others do not respond well, with most falling somewhere in between. Further research is needed to understand these differences fully.

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Chapter 17

Nursing Pain Care for Palliative or Terminally Ill Patients

1. Introduction

1.1. Common and distressing symptom: Pain is a common and distressing symptom in palliative care. Persistent pain can lead to depression, anxiety, and sleep disorders, affecting the patient's daily life, interpersonal interactions, and quality of life.

1.2. Complex nature of pain: Pain in palliative terminally ill patients (hereafter referred to as palliative patients) is influenced by biological (physical), psychological (emotional), spiritual, and social factors, making it complex and difficult to treat.

1.3. Comprehensive pain management: Effective pain relief for palliative patients requires accurate pain assessment and a holistic approach to pain management that addresses the total pain experience, which includes physical, emotional, spiritual, and social aspects. This goal can be achieved through interdisciplinary integrated pain management.

1.4. Nursing care overview: This chapter outlines the nursing care strategies for managing pain in palliative patients.

2. Goals of palliative nursing pain care

Goals of nursing pain care

01 Enable patients or their family members to implement effective pain relief measures under the guidance of nursing staff

02 Alleviate the patient's pain index or intensity to an acceptable leve

03 Experience pain relief during awake or rest periods

04 Improve sleep quality and enhance overall

05 Be able to engage in daily activities under pain-free or mildly painful conditions

3. Pain assessment

3.1. Pain assessment is a critical step in providing effective pain management. Proper assessment and management can significantly alleviate pain.

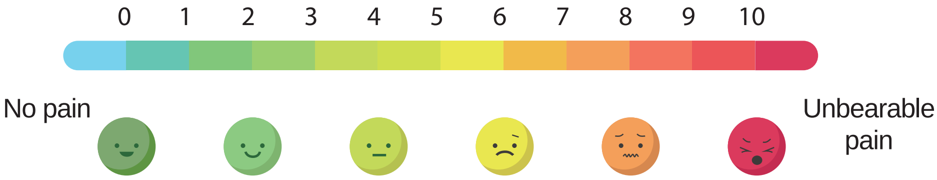
3.2. Pain is a subjective experience; thus, its presence and intensity should be measured based on the patient's self-report. The assessment aims to understand the current significance of the pain for the patient, based on information provided by the patient or their family, along with relevant tests and examinations. The results of the assessment help determine the possible causes of pain, allowing for personalized pain management planning.

3.3. The appropriate assessment tools should be used according to the patient's cognitive and conscious state.

3.4. A thorough pain assessment should cover biological, psychological, and social aspects, including personal medical history, detailed pain history, medication history, and multi-faceted evaluations to identify the source of pain. Proper diagnostic tests should be conducted to clarify the pain source and understand the patient's or family's expectations regarding pain management.

3.5. Commonly used pain assessment scales are illustrated in Figure 1.

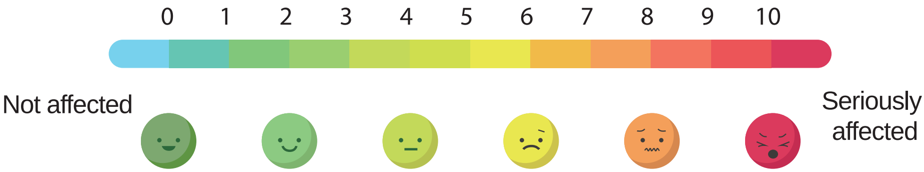
Figure 1 . Assessment of pain severity (numerical scale, with relieve 10 points)



Note: The assessed items may include: at rest, during activity, at worst pain, at least pain, after medication, and after treatment; it is also possible to evaluate the overall average within a day.

3.6. Psychological and emotional states, as well as cultural and social backgrounds, can influence how pain is experienced and expressed. These factors subsequently impact the quality of daily life. Commonly used scales to measure the impact of pain on daily activities are illustrated in Figure 2.

Figure 2. The extent to which daily life is affected by pain (numerical scale, with 10 points)



Note: Items evaluated can include:

(1) Assessment of Independence in Daily Living Activities: Activities such as bathing, dressing, toileting, mobility, and eating.

(2) Assessment of Functional Disability: Tasks such as household chores, school/work participation, social activities, leisure, sexual function, and self-care.

(3) Assessment of Impact on Daily Routines: Factors such as enjoyment of life, overall activity levels, sleep, and mood.

3.7. Assessing pain in elderly and dementia patients can be challenging due to cognitive impairments that affect communication and pain evaluation. Standardized tools are necessary, and regular, ongoing assessments are crucial (see Extended Reading 2 for more details).

3.8. Continuous assessment and monitoring of patients' responses to both pharmacological and non-pharmacological pain management methods are essential.

4. Pain management measures

4.1. Instruct patients or their families to actively assess and record pain levels to provide a reference for medical treatment.

4.2. Educate patients or families on the proper use of medications, such as skin patches or buccal tablets, and identify and assess any side effects.

4.3. Teach patients or families to recognize signs of medication overdose, dependence, or addiction.

4.4. Advise patients on using non-pharmacological treatments in addition to medications, such as listening to relaxing or favorite music, adjusting to more comfortable and less painful positions, massage, acupressure, and applying heat (avoiding heat on inflamed areas).

4.5. Instruct caregivers on providing appropriate massage therapy. Massage is generally safe for most palliative/end-of-life patients but should be avoided in cases of bone metastasis, fractures, or abdominal tumors.

4.6. Offer appropriate aromatherapy. While research indicates this therapy does not significantly reduce pain, it can alleviate depression, anxiety, and improve sleep and fatigue.

4.7. Lead patients in deep breathing relaxation techniques, meditation, or prayer, and guide them toward positive and proactive thinking.

4.8. Listen to patients and give them opportunities to express their emotions, helping to reduce pain or increase pain tolerance by alleviating fear and anxiety.

4.9. Arrange for key relatives or friends to visit and provide emotional support, enhancing the patient's psychological and spiritual wellbeing.

4.10. Ensure soft lighting and a quiet environment to make the patient feel safe.

4.11. Refer patients with psychological or spiritual care needs to psychologists, chaplains, or spiritual care providers.

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Chapter 18

End-of-Life Care and Pain Management

1. Introduction

1.1. According to the World Health Organization, palliative care provides physical, psychological, and spiritual support to patients (including adults and children) and their families facing incurable progressive diseases. This holistic approach addresses total pain (physical, emotional, social, and spiritual pain) through comprehensive team-based care, aiming for a peaceful end-of-life experience for both the patient and their family.

1.2. The Ministry of Health and Welfare in Taiwan defines palliative care as medical care aimed at alleviating or eliminating the biological (physical), psychological, and spiritual suffering of terminally ill patients to improve their quality of life.

1.3. The "Hospice Palliative Care Act," enacted in 2000 and revised multiple times, ensures that terminally ill patients in Taiwan can autonomously refuse cardiopulmonary resuscitation (CPR) and life-sustaining treatments to avoid unnecessary suffering at the end of life.

1.4. Enacted in 2016 and effective from 2019, this act safeguards patients' medical autonomy, promoting informed decision-making and dignified end-of-life care. It allows individuals with full legal capacity to sign an "Advance Medical Decision" after participating in advance care planning consultations. This decision ensures that individuals with terminal illnesses, irreversible comas, permanent vegetative states, severe dementia, or other severe conditions as announced by the authorities, have the right to refuse life-sustaining treatments and artificial nutrition and hydration.

1.5. Palliative care encompasses comprehensive support in biological (physical), psychological, spiritual, and social aspects, following the "Five Whole Care" model: whole person, whole family, whole team, whole process, and whole community. Physical care includes both pharmaceutical and non-pharmaceutical treatments to manage symptoms caused by diseases, and various palliative care services (e.g., wound care, pain management, edema care, end-of-life care). In psychological, spiritual, and social dimensions, the palliative care team provides counseling and support by assessing the needs and issues faced by patients and their families.

1.6. This chapter focuses on symptom management and pain relief for terminally ill patients.

2. Definitions

2.1. Advance Medical Care Consultation (A dynamic discussion process involving the medical team):

(1) Conducted in accordance with the Patient Right to Autonomy Act.

(2) Refers to the communication process between the patient, medical personnel, family members, or other relevant individuals. This process involves discussing the patient's choices regarding "life-sustaining treatments" and "artificial nutrition and hydration" when the patient is under certain clinical conditions, unconscious, or unable to express their wishes clearly.

2.2. Advance Medical Decision (A legally binding document signed by the patient):

It is a written statement made after an "advance care planning consultation," indicating the patient's wishes regarding the acceptance or refusal of life-sustaining treatments, artificial nutrition and hydration, or other related medical care and end-of-life preferences when under specific clinical conditions.

3. Common symptoms of terminally ill patients

3.1. Increasing weakness and frequent bed rest.

3.2. Drowsiness throughout the day with increasing sleep time.

3.3. Poor appetite, potentially leading to the inability to eat.

3.4. Gradually decreasing consciousness, confusion, agitation, and even hallucinations.

3.5. Irregular breathing patterns, possibly including apnea.

3.6. Throat gurgling sounds.

3.7. Cold or swollen extremities, with the appearance of purplish mottling (marble-like skin).

3.8. Possible mild fever, reduced urine output, or other symptoms.

4. Assessment of terminally ill patients

When it is recognized that a patient may be approaching the end of life:

4.1. Assessment and documentation: Evaluate and document the patient's condition, including levels of consciousness, food intake, respiratory rate, blood pressure, heart rate, urine output, and changes in other symptoms.

4.2. Understanding needs: Assess the patient's physiological, psychological, social support, and spiritual needs, and determine what additional medical care services can be provided.

4.3. Understanding perspectives: Understand the patient's knowledge of their disease progression, thoughts, and expectations for medical care.

4.4. Identifying wishes: Determine if the patient has any remaining wishes they hope to fulfill.

5. Communication and shared decision-making with the patient/family

5.1. Understanding the terminal stage: The medical team will assist the patient and family in understanding that the illness has progressed to the terminal stage, but it is challenging to accurately predict the time of death.

5.2. Concept of advance medical directive: Establish the concept of an "Advance Medical Decision," which includes understanding that there are choices available for subsequent treatments, such as selecting the contents of life-sustaining treatments and decisions regarding artificial nutrition and hydration (see Table 1).

5.3. Personalized care plans: Based on the cultural, religious, or spiritual needs of the patient and family, arrange personalized follow-up care, including the content and items of care, the choice of end-of-life location, wishes, people they want to see, tasks to complete, and personal concerns.

5.4. Managing expectations: It is often challenging to fulfill all of the patient's wishes. For items that are difficult to achieve, the medical team should communicate this truthfully and discuss alternative options with the patient, ensuring that the patient maintains a sense of autonomy over their life.

意願人：

預立醫療決定書

本人＿＿＿＿＿＿＿＿＿＿＿＿(正楷簽名)經「預立醫療照護諮商」，已經清楚瞭解「病人自主權利法」，賦予病人在特定臨床條件下，接受或拒絕維持生命治療，或人工營養及流體餵養的權利。本人作成預立醫療決定(如第一部分、第二部分及附件)，事先表達個人所期待的臨終醫療照護模式，同時希望親友尊重我的自主選擇。

意願人

姓名：＿＿＿＿＿＿＿＿＿＿＿＿＿＿簽署：＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿

國民身分證統一編號/居留證或護照號碼：＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿

住址：＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿

電話：＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿

日期：中華民國＿＿＿＿年＿＿＿＿月＿＿＿＿日　　　　　　時間：＿＿＿時＿＿＿分

見證或公證證明

我選擇以下列方式完成預立醫療決定之法定程序（請擇一進行）：

□ 1、二名見證人在場見證：

見證人 1　簽署：＿＿＿＿＿＿＿＿＿＿關係：＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿

連絡電話：＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿

國民身分證統一編號/居留證或護照號碼：＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿

見證人 2　簽署：＿＿＿＿＿＿＿＿＿＿＿＿＿＿關係：＿＿＿＿＿＿＿＿＿＿＿＿＿＿

連絡電話：＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿

國民身分證統一編號/居留證或護照號碼：＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿

日期：中華民國＿＿＿＿＿年＿＿＿＿月＿＿＿＿日

□ 2、公證：

公證人認證欄位：

日期：中華民國＿＿＿年＿＿＿月＿＿＿日

說明：

一、見證人必須具有完全行為能力，且親自到場見證您是出於自願、並無遭受外力脅迫等情況下簽署預立醫療決定（病人自主權利法第九條第一項第二款）。

二、見證人不得為意願人所指定之醫療委任代理人、主責照護醫療團隊成員、以及繼承人之外的受遺贈人、遺體或器官指定之受贈人、其他因意願人死亡而獲得利益之人（病人自主權利法第九條第四項）。

三、根據公證法第二條之規定，公證人因當事人或其他關係人之請求，就法律行為及其他關於私權之事實，有作成公證書或對於私文書予以認證之權限。公證人對於下列文書，亦得因當事人或其他關係人之請求予以認證：一、涉及私權事實之公文書原本或正本，經表明係持往境外使用者。二、公、私文書之繕本或影本。

意願人：

第一部分 醫療照護選項

臨床條件	醫療照護方式	我的醫療照護意願與決定 (以下選項，均為單選)
一、末期病人	維持生命治療	1、□我不希望接受維持生命治療。 2、□我希望在(一段時間)＿＿＿＿＿內，接受維持生命治療的嘗試，之後請停止；但本人或醫療委任代理人得於該期間內，隨時表達停止的意願。 3、□如果我已經意識昏迷或無法清楚表達意願，由我的醫療委任代理人代為決定。 4、□我希望接受維持生命治療。
	人工營養及流體餵養	1、□我不希望接受人工營養及流體餵養。 2、□我希望在(一段時間)＿＿＿＿＿內，接受人工營養及流體餵養的嘗試，之後請停止，但本人或醫療委任代理人得於該期間內，隨時表達停止的意願。 3、□如果我已經意識昏迷或無法清楚表達意願，由我的醫療委任代理人代為決定。 4、□我希望接受人工營養及流體餵養。
二、不可逆轉之昏迷	維持生命治療	1、□我不希望接受維持生命治療。 2、□我希望在(一段時間)＿＿＿＿＿內，接受維持生命治療的嘗試，之後請停止；但醫療委任代理人得於該期間內，隨時表達停止的意願。 3、□請由我的醫療委任代理人代為決定。 4、□我希望接受維持生命治療。
	人工營養及流體餵養	1、□我不希望接受人工營養及流體餵養。 2、□我希望在(一段時間)＿＿＿＿＿內，接受人工營養及流體餵養的嘗試，之後請停止；但醫療委任代理人得於該期間內，隨時表達停止的意願。 3、□請由我的醫療委任代理人代為決定。 4、□我希望接受人工營養及流體餵養。
三、永久植物人狀態	維持生命治療	1、□我不希望接受維持生命治療。 2、□我希望在(一段時間)＿＿＿＿＿內，接受維持生命治療的嘗試，之後請停止；但醫療委任代理人得於該期間內，隨時表達停止的意願。 3、□請由我的醫療委任代理人代為決定。 4、□我希望接受維持生命治療。
	人工營養及流體餵養	1、□我不希望接受人工營養及流體餵養。 2、□我希望在(一段時間)＿＿＿＿＿內，接受人工營養及流體餵養的嘗試，之後請停止；但醫療委任代理人得於該期間內，隨時表達停止的意願。 3、□請由我的醫療委任代理人代為決定。 4、□我希望接受人工營養及流體餵養。

意願人：

臨床條件	醫療照護方式	我的醫療照護意願與決定 (以下選項，均為單選)
四、極重度失智	維持生命治療	1、□我不希望接受維持生命治療。 2、□我希望在(一段時間)________內，接受維持生命治療的嘗試，之後請停止；但醫療委任代理人得於該期間內，隨時表達停止的意願。 3、□請由我的醫療委任代理人代為決定。 4、□我希望接受維持生命治療。
	人工營養及流體餵養	1、□我不希望接受人工營養及流體餵養。 2、□我希望在(一段時間)________內，接受人工營養及流體餵養的嘗試，之後請停止；但醫療委任代理人得於該期間內，隨時表達停止的意願。 3、□請由我的醫療委任代理人代為決定。 4、□我希望接受人工營養及流體餵養。
五、其他經中央主管機關公告之疾病或情形	維持生命治療	1、□我不希望接受維持生命治療。 2、□我希望在(一段時間)________內，接受維持生命治療的嘗試，之後請停止；但本人或醫療委任代理人得於該期間內，隨時表達停止的意願。 3、□如果我已經意識昏迷或無法清楚表達意願，由我的醫療委任代理人代為決定。 4、□我希望接受維持生命治療。
	人工營養及流體餵養	1、□我不希望接受人工營養及流體餵養。 2、□我希望在(一段時間)________內，接受人工營養及流體餵養的嘗試，之後請停止；但本人或醫療委任代理人得於該期間內，隨時表達停止的意願。 3、□如果我已經意識昏迷或無法清楚表達意願，由我的醫療委任代理人代為決定。 4、□我希望接受人工營養及流體餵養。

意願人：

第二部分 提供預立醫療照護諮商之醫療機構核章證明

根據病人自主權利法，意願人____________________________________於中華民國_________年_________月_________日完成預立醫療照護諮商，特此核章以茲證明。

醫療機構核章欄位：

中華民國_________年________月________日

意願人：

附件、醫療委任代理人委任書（若有指定，請選填）

本人（正楷簽名）＿＿＿＿＿＿＿＿＿＿＿茲委任＿＿＿＿＿＿＿＿＿＿(擔任我的第＿＿＿＿＿順位醫療委任代理人)，執行病人自主權利法第十條第三項相關權限。

【受委任之人】正楷簽名：＿＿＿＿＿＿＿＿＿＿＿
簽署日期：中華民國＿＿＿年＿＿＿月＿＿＿日
國民身分證統一編號/居留證或護照號碼： 出生年月日：中華民國＿＿＿年＿＿＿月＿＿＿日 電 話 號 碼： 住（居） 所：

（本表若不敷使用，請另行複印）

- 病人自主權利法「醫療委任代理人」相關條文：

壹、第十條（醫療委任代理人之要件與權限）

意願人指定之醫療委任代理人，應以二十歲以上具完全行為能力之人為限，並經其書面同意。

下列之人，除意願人之繼承人外，不得為醫療委任代理人：

一、意願人之受遺贈人。

二、意願人遺體或器官指定之受贈人。

三、其他因意願人死亡而獲得利益之人。

醫療委任代理人於意願人意識昏迷或無法清楚表達意願時，代理意願人表達醫療意願，其權限如下：

一、聽取第五條之告知。

二、簽具第六條之同意書。

三、依病人預立醫療決定內容，代理病人表達醫療意願。

醫療委任代理人有二人以上者，均得單獨代理意願人。

醫療委任代理人處理委任事務，應向醫療機構或醫師出具身分證明。

貳、第十一條（醫療委任代理人之終止委任及解任）

醫療委任代理人得隨時以書面終止委任。

醫療委任代理人有下列情事之一者，當然解任：

一、因疾病或意外，經相關醫學或精神鑑定，認定心智能力受損。

二、受輔助宣告或監護宣告。

參、第十三條（意願人申請更新註記之情形）

意願人有下列情形之一者，應向中央主管機關申請更新註記：

一、撤回或變更預立醫療決定。

二、指定、終止委任或變更醫療委任代理人。

6. Providing care to alleviate clinical discomfort

6.1. Medication review: For patients nearing the end of life, the palliative care team will reassess the medications being used, retaining those that alleviate symptoms and reducing unnecessary medications. They will also help patients choose appropriate administration methods. For terminally ill patients, subcutaneous injections are a safe and convenient route.

6.2. Life-sustaining treatment decisions: Discuss and define whether to continue life-sustaining treatments and select the specific interventions.

6.3. Continuous assessment: The palliative care team will continuously evaluate and predict potential complications such as bleeding or aspiration pneumonia, to appropriately manage the patient's discomfort.

6.4. Additional arrangements: This includes pre-end-of-life arrangements, ensuring spiritual peace at the end of life, providing grief support, and caring for the bereaved family members.

7. Pain management

7.1. Addressing pain: Not all patients experience pain in their final life stages. However, if pain is present, the palliative care team will effectively treat the underlying causes.

7.2. Common causes of pain:

(1) Persistent pathological fractures.

(2) Oral thrush (which may cause oral and throat pain).

(3) Urinary retention or constipation.

(4) Pressure ulcers leading to wounds.

(5) Pre-existing chronic pain or new acute pain conditions (e.g., brain/cardiovascular/chest/abdominal emergencies).

8. Management of dyspnea/respiratory distress

8.1. Treatable causes: For conditions that can be cured or significantly improved, such as pulmonary edema or pleural effusion, the palliative care team will provide appropriate treatment.

8.2. Symptom relief: For causes of dyspnea that cannot be cured or significantly improved, efforts should focus on relieving the symptom. Opioids may be used to alleviate dyspnea, and anti-anxiety medications can be used if necessary to reduce anxiety.

9. Management of nausea and vomiting

9.1. Identify the causes of nausea and vomiting

(1) Is it caused by medication?

(2) Is it due to radiation or chemotherapy?

(3) Is it caused by psychological factors?

(4) Are there biochemical causes such as electrolyte imbalances, metabolic toxins, or hypercalcemia?

(5) Is it due to increased intracranial pressure?

(6) Is it caused by decreased gastrointestinal motility?

(7) Is it due to bowel obstruction?

9.2. Determine the cause and discuss treatment options with the patient and family

(1) Treat curable causes.

(2) Provide palliative care for incurable causes to alleviate symptoms.

10. Management of anxiety, delirium, and agitation

10.1. Identify underlying causes: Symptoms may arise from diarrhea, bladder distension, pain, metabolic imbalances (electrolytes, hydration, acid-base balance, blood sugar), or psychological factors.

10.2. Symptom relief: The palliative care team may use anti-anxiety medications to treat anxiety and agitation, and antipsychotic medications to manage delirium and agitation.

10.3. Specialist referral: If initial treatments are ineffective, refer to appropriate medical specialists.

11. Management of terminal respiratory secretions (death rattle)

11.1. Cause: In terminally ill patients, muscle weakness can lead to an accumulation of oral secretions at the back of the throat, causing a rattling sound.

11.2. Comfort measures: This sound does not cause discomfort or choking. Suctioning may be attempted but should not be forced, as it can cause more discomfort.

11.3. Positioning: Elevating the head of the bed or positioning the patient on their side can help secretions drain, reducing the rattling sound.

11.4. Medications: Some medications can help reduce secretions.

12. Management of other physical symptoms

12.1. Common symptoms: Reduced food intake, increased sleep, unstable blood pressure, poor limb circulation, decreased sensory function, reduced urine output, and incontinence.

12.2. Treatment approach: Prioritize treating curable conditions. For incurable conditions, focus on alleviating discomfort.

13. Psychological care

13.1. Demoralization syndrome: Common in terminally ill patients, characterized by persistent hopelessness, helplessness, and loss of meaning or purpose in life.

13.2. Differentiation from depression: Unlike depression, which involves a pervasive lack of interest and affect, patients with demoralization syndrome may still react to humor but feel life lacks meaning.

13.3. Supportive measures: Encourage patient participation in life decisions, use cognitive-behavioral therapy, provide continuous companionship, and actively listen to help them find a sense of purpose and overcome demoralization.

14. Spiritual care

14.1. Life review and contemplation: As patients approach the end of life, they often engage in life reviews and think about what lies beyond death.

14.2. Questions of meaning: Patients frequently ponder the meaning of life, the significance of suffering, and what constitutes a valuable life.

14.3. Spirituality beyond religion: While religious beliefs are related to spirituality, spirituality encompasses a broader range of personal values and beliefs.

14.4. Common spiritual struggles at the end of life:

(1) Loss of self-esteem.

(2) Giving up on oneself.

(3) Unresolved feelings: reluctance, worry, regret, and guilt.

(4) Fear of death.

(5) Unfulfilled wishes.

14.5. Facing death: Many people avoid talking about death, leading to confusion and difficulty in accepting it when it becomes imminent. Overcoming the fear of death is a key aspect of spiritual care at the end of life.

14.6. Overcoming the fear of death:

(1) Accept death proactively, rather than being overwhelmed by bad news.

(2) Prepare for what lies ahead and make necessary arrangements.

(3) Enhance the quality of life and find meaning and fulfillment.

(4) Contribute actively and independently to reinforce inner strength and happiness.

(5) Engage in four key conversations with family and friends (expressing love, gratitude, farewells, and apologies) to address unresolved issues and spiritual unrest.

(6) Rely on religious faith to strengthen hope and inner peace.

15. Spiritual comfort at the end of life, grief support, and bereavement care

15.1. Identify significant life events: Family members can help list important life events, roles, and values that mattered to the patient.

15.2. Provide hopeful companionship: Find ways to accompany the patient with small, enduring hopes, ensuring they do not feel like a burden.

15.3. Facilitate reconciliation: Help the patient connect with people they wish to thank or apologize to, and create a conducive environment for these interactions. Encourage the patient to express regrets without forcing reconciliation.

15.4. Continuous expression of love: Ensure the patient continually feels loved and can express love to others.

15.5. Explore the relationship with the divine: Assist the patient in contemplating their relationship with a higher power and guide close companions on how to respond to existential questions without imposing religious pressure.

15.6. Grief support for family members: Observe and support family members experiencing grief during the patient's final moments. Most people adjust to loss within weeks or months, but about 7-20% may experience prolonged grief due to the unique significance of the deceased or the circumstances of their passing. These individuals may need psychological care and support if they exhibit signs of maladjustment such as depression, substance abuse, social withdrawal, or suicidal ideation.

15.7. Identifying high-risk families: The palliative care team will identify family members at high risk of severe grief, plan appropriate times and methods for bereavement care, choose suitable caregivers, and ensure psychological support is available when needed.

Further Reading

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2. Healthcare Improvement Scotland (HIS), NHS Scotland. Scottish Palliative Care Guidelines. Pain Management. 2019. https://www.palliativecareguidelines.scot.nhs.uk/guidelines/pain/pain-management.aspx

3. Yorkshire and the Humber End of Life Care Group, NHS England. A Guide to Symptom Management in Palliative care. 2019.
   https://www.yorkhospitals.nhs.uk/seecmsfile/?id=4770

4. BC Centre for Palliative Care. B.C. Inter-Professional Palliative Symptom Management Guidelines-Pain. 2019.
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5. BC Guidelines and Protocols and Advisory Committee (GPAC). Palliative Care for the Patient with Incurable Cancer or Advanced Disease. Part 2: Pain and Symptom Management. 2017.
   https://www2.gov.bc.ca/assets/gov/health/practitioner-pro/bc-guidelines/palliative2.pdf

6. DynaMed. Pain Management in Palliative Care. EBSCO Information Services.
   https://www.dynamed.com/management/pain-management-in-palliative-care-19

7. Dana Farber Cancer Institute/Boston Children's Hospital Pediatric Advanced Care Team. Pediatric Palliative Care Approach to Pain & Symptom Management. 2020.
   https://pinkbook.dfci.org/assets/docs/blueBook.pdf

8. BC Centre for Palliative Care. B.C. Inter-Professional Palliative Symptom Management Guidelines: Nurturing Psychosocial and Spiritual Well-Being. 2019.
   https://bc-cpc.ca/wp-content/uploads/2019/11/ColorPsychosocialGuideNov2019a.pdf

9. 台灣安寧緩和醫學學會。衰弱老人安寧緩和醫療照護指引。衛生福利部。2020。
   https://drive.google.com/file/d/1ECNsCyBVVXIzgWyJHjJ6-zmr42aWB8wb/view?usp=sharing

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Chapter 19

Traditional Chinese Medicine (TCM) for Pain Management in Palliative Care Patients

1. Introduction

Renowned Italian scholar Arturo Castiglioni once said, "Medicine was born from the first cry of human suffering and the need to alleviate that suffering." Pain has always been closely associated with our daily lives, and relieving pain was one of the earliest goals of medicine. Its importance in palliative care is unparalleled. Palliative care aims to improve the quality of life for patients and their families when facing life-threatening illnesses. Through early identification, comprehensive assessment, and holistic medical approaches, pain management seeks to prevent and alleviate biological (physical) suffering and address psychological, social, and spiritual distress for both patients and their families.

2. TCM perspectives on pain

2.1. Pain is a subjective discomfort and one of the most common reasons for seeking medical care. The complexity of pain experienced by palliative care patients far exceeds that of the general population. Pain is not an isolated symptom; it impacts sleep, emotions, and daily living abilities. Traditional Chinese Medicine has been observing pain for thousands of years. One of the four classical TCM texts, "Huangdi Neijing" (The Yellow Emperor's Inner Canon), includes a dedicated chapter on pain, "Discussion of Pain," which covers symptoms, causes, and treatment principles for various types of pain, from musculoskeletal to visceral pain. A significant portion of palliative care patients suffer from cancer-related pain. Statistics show that over 51% of cancer patients experience pain, and in end-stage cancer patients, 60-90% face pain issues, making it their primary symptom.

2.2. Modern TCM integrates classical knowledge, condensing the causes of pain into two main categories: "pain due to obstruction" and "pain due to insufficiency." "Pain due to obstruction" refers to pain caused by the obstruction of qi and blood circulation, while "pain due to insufficiency" arises when tissues and organs do not receive adequate qi and blood supply. These two causes often have a cause-and-effect relationship; for example, circulatory obstruction can lead to localized insufficient qi and blood perfusion, or overall qi and blood deficiency can cause local circulatory obstruction. The actual causes and proportions of pain must be diagnosed by a TCM practitioner through the four diagnostic methods.

3. Modalities of TCM for pain management

TCM offers various types of treatments for pain, generally categorized into internal and external methods. Internal methods involve taking Chinese herbal medicine, available in Taiwan as concentrated herbal powders covered by health insurance or as decoctions of medicinal herbs, which require out-of-pocket payment. External methods encompass a wide range of techniques commonly used in modern TCM, such as acupuncture, laser acupuncture, cupping, topical applications, bloodletting, acupressure, and ear acupressure. Compared to internal methods, external treatments do not involve medication intake, thus reducing the burden on the gastrointestinal system, which aligns well with the principles of palliative care for terminal patients.

3.1. Chinese herbal medicine

Chinese herbal medicine has existed for thousands of years and has been proven effective in pain management through numerous studies. For example, herbs like corydalis, ku-dou-zi (bitter bean), and fang-ji have notable analgesic properties. Combining multiple herbs is more effective than using a single herb, adhering to the TCM principle of "Emperor, Minister, Assistant, and Courier" to enhance the analgesic effect. Clinical diagnosis involves "inspection, listening and smelling, inquiry, and palpation," and treatment is based on the most likely cause of the patient's pain determined through this process.

3.2. Acupuncture and acupressure

Acupuncture is one of the most popular TCM treatments worldwide. TCM believes that the meridian system is responsible for transporting and distributing qi and blood throughout the body. By stimulating acupoints through acupuncture or acupressure, the flow of qi and blood within the meridians can be improved, maintaining balance and stability in the body's organs and tissues. This can alleviate meridian blockages, treat diseases, and improve symptoms, restoring normal physiological functions. In 2008, the National Institutes of Health (NIH) and the Food and Drug Administration (FDA) in the United States jointly announced that acupuncture effectively controls pain and nausea. Acupuncture has been found to reduce pain sensitivity, promote the brain's release of endorphins, improve peripheral blood circulation, and relax muscles and surrounding tissues to achieve analgesic effects. Acupressure is a gentler method similar to acupuncture, stimulating acupoints through pressure to produce therapeutic effects.

3.3. Auricular acupressure

Auricular therapy utilizes the connections between the auricle and the body's organs, meridians, tissues, and limbs to regulate physiological functions. From a modern medical perspective, pressing acupoints on the ear stimulates lymphatic vessels, blood vessels, and nerves in the ear, sending signals to the brain to adjust physiological functions. French physician Paul Nogier was the first to propose and publish research on the correspondence between the auricle and body positions. In 1957, he suggested that specific points or areas on the ear correspond to certain organs or systems in the body. The shape of the auricle resembles an inverted fetus, and specific corresponding acupoints can be stimulated to adjust organ functions, prevent diseases, or treat symptoms. Auricular acupressure often uses magnetic beads or plant seeds fixed on specific acupoints with small adhesive patches, instructing patients to apply pressure regularly. Typically, pressure is applied for 3-5 minutes, 3-5 times a day, with the patches changed every 3-7 days. It is essential to keep the patches dry to avoid moisture. Studies have shown that auricular acupressure effectively calms, relieves pain, and lowers blood pressure. Compared to acupuncture, auricular acupressure is milder and has a broader range of applications.

3.4. Laser acupuncture

Laser acupuncture uses low-energy lasers to stimulate acupoints, achieving therapeutic effects through photobiostimulation. Unlike traditional acupuncture, laser acupuncture is non-invasive, without the risk of bleeding, local soreness, or bruising.

3.5. Cupping

Cupping has a long history in TCM, dating back to the third century BCE. It is a safe and easy-to-perform external treatment method used for various conditions, from musculoskeletal injuries to internal diseases like neurological, endocrine, cardiovascular, and respiratory disorders. Cupping involves creating negative pressure on the skin surface, causing local microvascular rupture, promoting local tissue metabolism, circulation, and regeneration. It enhances blood circulation, harmonizes the body's energies, and improves immune function. Additionally, it can trigger the brain to release endorphins and other neurotransmitters, providing pain relief.

3.6. Topical applications of chinese herbal medicine

Topical applications often use medicinal plasters or patches. The advantage of topical treatments lies in transdermal absorption, which reduces gastrointestinal and hepatic load compared to oral medications. Typically, medicinal powders are mixed with excipients to form a paste applied to acupoints or painful areas. Topical treatments require a prescription from a TCM physician, and some medical institutions offer pre-mixed medicinal plasters for patient use.

4. TCM management for each pain condition

4.1. Muscle pain

Palliative care patients often experience various types of muscle pain due to cancer invasion, reduced mobility, and muscle atrophy. The "Yellow Emperor's Inner Canon" states, "Prolonged lying injures qi, prolonged sitting injures the flesh." Therefore, for muscle pain caused by prolonged lying or sitting in palliative patients, acupuncture points that replenish qi and nourish the flesh are often stimulated, such as Zusanli (ST36) on the Stomach Meridian, Yinlingquan (SP9) on the Spleen Meridian, Hegu (LI4) on the Large Intestine Meridian, and Yanglingquan (GB34) on the Gallbladder Meridian. Zusanli is a primary point for qi replenishment, while Yinlingquan enhances its effect. Hegu has been shown in many studies to have significant analgesic effects. Yanglingquan, known as the "meeting point of muscles and tendons," is used to treat muscle and tendon pain and can be applied for general muscle soreness and various types of neuropathic pain.

4.2. Bone pain from cancer metastasis

Pain from cancer metastasis to the bones is often severe, and even slight movements or no movement can cause intense pain. This pain significantly reduces mobility and quality of life. Different distal points are used for various locations of bone pain, but caution is needed as patients with bone metastasis have a higher risk of fractures. Gentle pressing is recommended, with reduced time and intensity. For bone pain in the shoulder, neck, or back, cupping can be added to improve local circulation and alleviate pain.

4.3. Headache

Patients with brain cancer or brain metastasis often suffer from headaches caused by increased intracranial pressure or invasion of the meninges and blood vessels. These headaches are usually worst upon waking and can worsen with exertion, coughing, sneezing, or bending forward, often accompanied by nausea and vomiting, with some relief after vomiting. TCM practitioners often press Zusanli (ST36) to enhance brain circulation and relieve headaches. Lieque (LU7) on the Lung Meridian, known for treating head and neck issues, is also used. The combination of Hegu (LI4) and Taichong (LR3), forming the "Four Gates," is commonly used for treating head pain.

4.4. Abdominal pain

Abdominal pain in palliative care patients can be caused by cancer metastasis, digestive system ulcers, motility disorders, inflammation, or gastroenteritis. These conditions are challenging to diagnose in patients with multiple comorbidities. Pressing Hegu (LI4) can relieve pain, while Zhigou (SJ6) can be added for constipation to promote qi circulation and bowel movements. Zusanli

(ST36) and Baihui (GV20) can be used for diarrhea to lift yang and stop diarrhea. For upper abdominal pain, nausea, or vomiting, Neiguan (PC6) can be added. For lower abdominal pain, Qihai (CV6) and Guanyuan (CV4) on the Ren Meridian can be used to alleviate pain. If the abdomen is cold or accompanied by watery diarrhea, indicating yang deficiency in the lower burner, moxibustion on Shenque (CV8) is recommended.

4.5. Oral ulcer pain

Recurrent oral ulcers are common in palliative patients, affecting eating and mood. Pressing Hegu (LI4) can help relieve pain. The "Yellow Emperor's Inner Canon" states, "All pains and itching sores belong to the heart," suggesting that oral ulcers and related pain can be treated by stimulating the Heart Meridian points, specifically Shaofu (HT8), to reduce oral inflammation. Additionally, using a decoction of raw licorice as a mouthwash is recommended.

5. TCM management for side effects of pain medications

Cancer and palliative care patients often require opioid pain medications. These medications effectively relieve pain by inhibiting the central nervous system but also cause concerning side effects, such as constipation, loss of appetite, nausea, and vomiting. Below are common TCM acupuncture points recommended by practitioners to manage these side effects.

5.1. Constipation

Constipation caused by opioid pain medications is a particularly troubling symptom for patients. This issue does not improve over time and may even worsen, significantly impacting the patient's quality of life. TCM practitioners often stimulate meridians related to the spleen and stomach to alleviate constipation. Recommended points include Zusanli (ST36), Shangjuxu (ST37), Xiajuxu (ST39), and Yinlingquan (SP9). Additionally, Zhigou (SJ6) on the Sanjiao Meridian can be used to promote the movement of qi and stimulate gastrointestinal motility.

5.2. Loss of appetite, nausea, and vomiting

Loss of appetite is a common symptom in palliative patients nearing the end of life. For this, pressing Neiguan (PC6) and Zusanli (ST36), along with cupping near the back-shu points, can be effective. For patients experiencing nausea and vomiting, TCM addresses these symptoms by considering the stomach's role in food intake and digestion. The aforementioned points Neiguan (PC6) and Zusanli (ST36) are commonly used, with the addition of Fenglong (ST40) on the Stomach Meridian. Warm packs or moxibustion patches can also be applied to Zhongwan (CV12) and Xiawan (CV10).

6. Conclusion

TCM emphasizes "syndrome differentiation and treatment," meaning treatments are tailored to the individual's constitution and disease condition. For pain management, the primary approach is to identify the main cause of pain and treat accordingly: tonify deficiency, reduce excess, warm cold, and cool heat. Palliative care patients often present complex symptoms, with pain typically resulting from multiple factors. Modern pain management emphasizes holistic care, addressing the patient's biological (physical), psychological, spiritual, and social needs. TCM practitioners use comprehensive diagnostics through the four examinations (inspection, listening and smelling, inquiry, and palpation) to develop an appropriate treatment plan. Palliative care patients often prefer minimal medication use, so non-pharmacological treatments such as acupuncture, laser acupuncture, cupping, ear acupressure, and herbal patches are commonly employed. These methods do not burden the liver, kidneys, or gastrointestinal system, helping to alleviate discomfort and improve quality of life.

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Chapter 20

Doctor-Patient Communication and Shared Decision-Making

1. Introduction

Effective communication between doctors and patients can enhance understanding of the patient's condition and facilitate shared decision-making in disease treatment. Key topics for discussion and communication include:

1.1. What palliative care services are available?

1.2. What legal regulations govern palliative care?

1.3. Understanding pain.

1.4. Expressing pain.

1.5. How to choose the appropriate pain relief method?

1.6. Advantages and disadvantages of commonly used pain medications.

1.7. How to safely choose and use opioid medications?

1.8. Medical care considerations before the end of life.

1.9. Spiritual comfort, grief support, and bereavement care at the end of life.

2. What palliative care services are available?

2.1. What are the differences between palliative care and hospice care? What are the similarities and differences in care goals and content?

2.2. Who provides the care? What is included in individual care?

2.3. What groups are eligible for care?

2.4. Explanation of hospice inpatient care, hospice home care, and integrated hospice care.

3. What are the legal regulations regarding palliative care?

3.1. Introduction to the hospice palliative care act.

3.2. Introduction to the Patient Autonomy Act.

3.3. Similarities and differences between the hospice palliative care act and the patient autonomy act.

3.4. How to sign a Do-Not-Resuscitate (DNR) consent form or an advance directive?

3.5. When do the above documents take effect?

3.6. What is a medical proxy? What is its significance to the patient in medical and legal terms? When should a proxy be appointed? How to sign a proxy form?

3.7. Explanation of scenarios involving the right to refuse treatment and the duty to provide emergency care.

3.8. Regulations regarding organ donation and body donation.

4. Understanding pain

4.1. What are the common types of pain?

4.2. How does pain affect life and quality of life? How can it be measured?

4.3. What tests or examinations might be necessary?

4.4. What are the risk factors associated with pain?

4.5. What aspects of pain can be prevented?

5. Expressing pain

5.1. What methods or forms are used to assess the severity of pain?

5.2. How can patients accurately and thoroughly express their pain?

5.3. What methods are used to assess pain when patients cannot express it verbally?

6. Choosing the appropriate pain relief method

6.1. What are the goals and strategies for treating pain?

6.2. What are the commonly used pain relief methods and medications?

6.3. How can the effectiveness of pain medications be observed? How can caregivers help record this information?

6.4. Who are the potential members of the medical team, and what are their roles?

7. Common pain relief methods and medications: advantages and disadvantages

7.1. Stress relief techniques, aromatherapy, rehabilitation, sleep, exercise, nutrition, and spiritual support.

7.2. Introduction to non-opioid pain medications.

7.3. Introduction to opioid medications.

8. Choosing and safely using opioid medications

8.1. Introduction to the efficacy and side effects of individual opioid pain medications.

8.2. Addressing concerns about medication safety and addiction.

8.3. Proper storage and disposal of medications.

9. End-of-life care considerations

9.1. Treatment of symptoms.

9.2. Providing emotional support.

9.3. Offering spiritual care.

9.4. Explanation of administrative arrangements (including the issuance of death certificates and various medical certificates).

10. Spiritual comfort, grief support, and family care at the end of life

10.1. Understanding what important life events, roles, or values matter to the patient.

10.2. Identifying things that might help the patient maintain even a small, indomitable hope (ensuring the patient does not feel like a burden or is only left to suffer physically and emotionally).

10.3. Helping the patient express gratitude or apologies and speak about any regrets (without pressuring them to resolve these regrets).

10.4. Ways to continuously show love to the patient and help the patient express love to others.

10.5. Understanding the patient's relationship with a higher power and how to appropriately respond when the patient asks, "Where will I go?" or "Why did I get sick?" (without imposing religious pressure).

10.6. How to support grieving loved ones and identify signs of high grief risk.

10.7. Timing, methods, and providers of bereavement support; identifying available psychological care resources for those at high risk of grief.

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Chapter 21

Patient Self-Care

1. Introduction

During palliative care, patients can engage in self-care by following these guidelines:

1.1. What self-care methods can be used during palliative care?

1.2. What kind of records and self-assessments should be maintained?

1.3. How to maintain good sleep quality?

1.4. How to reduce stress and enhance stress resilience?

1.5. What psychological therapies/strategies can alleviate the perception of pain?

1.6. How to practice mindfulness-based stress reduction?

1.7. How to enrich the spirit?

1.8. How to seek help?

1.9. What nutritional and dietary considerations are important?

1.10. How to plan rehabilitation/exercise/daily activities?

1.11. How to arrange hobbies and leisure activities?

1.12. How to integrate, reconnect, and nurture relationships?

2. Self-care methods during palliative care

During palliative care, patients can adopt the following self-care methods:

2.1. Physical care: Regular bathing and changing into clean clothes can ensure skin cleanliness and hydration, which helps alleviate discomfort.

2.2. Comfortable living environment: Create a comfortable, quiet, and relaxing environment, avoiding irritating noises or strong lights to promote peace of mind and body.

2.3. Pain management: Follow the doctor's advice and take pain medication on time. If there is any discomfort, promptly inform the healthcare provider to adjust the medication dosage.

2.4. Breathing exercises: Learning deep breathing and diaphragmatic breathing can help relieve anxiety and increase oxygen intake, promoting relaxation.

2.5. Massage and light exercise: Gentle massages and light exercises help maintain body flexibility and reduce muscle tension.

2.6. Music and art therapy: Listening to music, appreciating art, or engaging in artistic creation can enhance mental well-being.

These methods can be adjusted based on individual conditions and comfort levels, focusing on finding peace of mind and body within the patient's capabilities.

3. What records and self-assessments should be done?

During the palliative period, patients can conduct the following records and self-assessments:

3.1. Symptom records: Daily records of pain, discomfort, appetite changes, and other symptoms to discuss and adjust treatment plans with healthcare providers promptly.

3.2. Emotional assessment: Regularly assess emotional states, including anxiety, depression, and acceptance of the illness. This helps identify and address emotional distress early.

3.3. Diet diary: Keep a record of dietary habits to ensure adequate nutrition intake. Collaborate with a nutritionist if there are special dietary needs.

3.4. Medication usage record: Accurately document medication use, including dosage, timing, and any adverse reactions. This helps healthcare providers adjust treatment plans.

These records and assessments help build a more effective care plan and enable patients to better understand their physical condition.

4. How to maintain good sleep quality

Maintaining good sleep quality is essential for a patient's physical and mental health and peace of mind. Here are some recommendations:

4.1. Establish a regular sleep schedule: Try to go to bed at the same time every night and wake up at the same time every day to help regulate the biological clock.

4.2. Create a comfortable sleep environment: Ensure the sleep environment is quiet, dark, cool, and comfortable. Avoid strong lights and irritating noises.

4.3. Avoid stimulants: Reduce caffeine, tea, and alcohol intake, especially in the evening. This helps minimize their impact on sleep.

4.4. Practice deep breathing and meditation: Engage in deep breathing or meditation exercises before bed to relax the mind and body and reduce pre-sleep anxiety.

4.5. Use sleep aids wisely: If needed, consult with a doctor to consider using sleep aids to improve sleep quality.

Good sleep quality positively affects physical recovery and mental health.

5. How to relieve stress and improve resilience

During palliative care, relieving stress and improving resilience are important self-care methods. Here are some suggestions:

5.1. Deep breathing and meditation: Learning deep breathing techniques and meditation can help relax the mind and body, reducing anxiety and stress.

5.2. Physical activity: Engage in moderate light exercise, such as walking or yoga, to release physical tension and promote blood circulation.

5.3. Psychological support: Seek counseling or join support groups to share feelings with others, which helps alleviate emotional burdens.

5.4. Set goals: Set small, achievable goals to maintain motivation and a sense of hope, while also diverting attention.

5.5. Engage in enjoyable activities: Cultivate and maintain activities of interest and enjoyment to enhance quality of life and emotional well-being.

5.6. Art therapy: Participate in artistic creation, such as painting or writing, to express emotions and shift focus.

Relieving stress and improving resilience require consistency and can be adjusted based on individual preferences and comfort levels.

6. What psychological therapies/strategies can alleviate the sensation of pain?

When facing pain, the following psychological therapies and strategies can be used to alleviate the sensation:

6.1. Cognitive Behavioral Therapy (CBT): Learn to identify and change negative thinking patterns to reduce emotional responses to pain.

6.2. Mindfulness: By practicing mindfulness, focus on present experiences to reduce anxiety about the pain.

6.3. Imagery and visualization: Try imagining yourself in a comfortable, quiet place or use visualization techniques (such as looking at photos or landscapes that bring joy) to divert attention and lessen pain.

6.4. Deep relaxation: Engage in deep relaxation exercises to relax different parts of the body, helping to reduce muscle tension and pain.

6.5. Music therapy: Listen to music or participate in music therapy activities to distract attention and enhance psychological pleasure.

These strategies may require some time and practice, so it is recommended to perform them under the guidance of healthcare professionals to ensure they suit individual conditions.

7. How to use mindfulness meditation to reduce stress?

Mindfulness is a psychological therapy that focuses on the present and accepts current experiences, which can be used to reduce stress. Here are some mindfulness stress-reduction methods:

7.1. Breath observation: Focus attention on breathing, feel each breath, and maintain calmness and relaxation.

7.2. Body scan: Gradually pay attention to each part of the body from head to toe, feeling and releasing tension in each area.

7.3. Mindful walking: Focus on the sensation of each step while walking, observing the feeling of each foot touching the ground.

7.4. Sitting meditation: Sit quietly in a calm environment, concentrate, observe the flow of thoughts, and accept the current psychological state without judgment.

7.5. Mindful eating: Focus on the taste, texture, and sensation of food while eating, slowly savoring each bite.

These mindfulness practices help reduce anxiety, enhance acceptance of current experiences, and promote a sense of psychological peace.

8. How to enrich the soul?

Enriching the soul can be a significant source of psychological support during palliative care. Here are some methods:

8.1. Spiritual practices: Engage in spiritual practices supported by personal faith or values, which may include prayer, meditation, or participating in religious ceremonies.

8.2. Sharing with Family and Friends: Share feelings, memories, and expressions of gratitude with loved ones to build connections and enhance spiritual fulfillment.

8.3. Spiritual guidance: Seek support from a spiritual mentor, pastor, or spiritual counselor to explore spiritual questions and find meaning.

8.4. Yoga and meditation: Practice yoga and meditation to connect the body, mind, and spirit, fostering inner peace.

8.5. Reading and writing: Read spiritual books, poetry, or express inner thoughts and feelings through writing to explore the spiritual dimension.

Enriching the soul is a deeply personal experience, so each person's approach may differ. The key is finding meaningful ways to enhance spiritual fulfillment.

9. How to seek assistance?

Seeking timely assistance during palliative care is crucial. Here are some methods:

9.1. Communication with the medical team: Maintain open and honest communication with the medical team, sharing changes in physical and psychological conditions.

9.2. Social workers and counseling: Work with social workers or counselors to explore emotional and psychological needs and receive appropriate support.

9.3. Family and friends: Share feelings with close family members and friends, allowing them to participate in the caregiving process, providing substantial support and companionship.

9.4. Palliative care team: If supported by a palliative care team, including home palliative care, long-term palliative care, and community resources, effective assistance can be provided to patients.

Seeking assistance not only helps meet physical and psychological needs but also provides substantial emotional and social support.

10. What to pay attention to in nutrition and diet?

During palliative care, the importance of nutrition and diet should not be overlooked. Here are some suggestions:

10.1. Adapt to tastes: Consider your own tastes and preferences, and choose easily digestible foods to ensure adequate nutrition intake.

10.2. Small, frequent meals: Opt for smaller, more frequent meals to distribute nutrient intake and reduce discomfort in the stomach.

10.3. Nutritional supplements: If needed, consider using nutritional supplements to ensure your body gets sufficient nutrients.

10.4. Hydration: Ensure adequate water intake to maintain hydration and alleviate dehydration.

10.5. Work with a nutritionist: Collaborate with a nutritionist to create a diet plan tailored to your individual needs and adjust nutrient intake based on your physical condition.

During palliative care, diet should prioritize comfort and satisfaction, and adjustments should be made according to individual circumstances.

11. How to arrange rehabilitation/exercise/daily activities?

Rehabilitation, exercise, and daily activities remain important during palliative care, even though adjustments may be necessary. Here are some suggestions:

11.1. Light exercise: Engage in moderate light exercise, such as walking or yoga, to maintain muscle flexibility and bodily functions.

11.2. Rehabilitation plan: If there are related rehabilitation needs, work with rehabilitation professionals to create a plan suitable for your personal situation.

11.3. Daily activities: Maintain daily activities such as light housekeeping, reading books, and listening to music to keep a variety of life experiences.

11.4. Posture adjustment: Regularly adjust your posture when sitting or lying down for extended periods to avoid muscle stiffness and discomfort.

11.5. Professional advice: Consult with your medical team based on your physical condition to ensure appropriate activity arrangements.

Even though the level of activity might decrease, it can still help maintain mental positivity and quality of life.

12. How to arrange interests and leisure?

During palliative care, interests and leisure activities can provide spiritual solace and emotional support. Here are some suggestions:

12.1. Cultivate interests: Spend time developing your interests, which might include reading, painting, appreciating music, or other personal hobbies.

12.2. Family activities: Participate in relaxing family activities, such as watching movies or playing games, to enhance closeness.

12.3. Nature activities: If physically possible, try outdoor activities like enjoying the scenery or listening to the sounds of nature to uplift your spirit.

12.4. Social activities: Engage in social activities and gatherings with friends or family to share laughter and memories.

12.5. Music therapy: Participate in music therapy activities or listen to uplifting music to improve your emotional state.

Activities related to personal interests can serve as emotional pillars, giving patients meaningful and fulfilling time during palliative care.

13. How to integrate and reconnect relationships with the four aspects of life (thankfulness, love, apology, and farewell)?

During palliative care, relationships become especially important. Here are some suggestions:

13.1. Honest communication: Maintain honest communication with family, friends, and the medical team, sharing your inner feelings and needs.

13.2. Create memories: Create beautiful memories with loved ones to foster shared emotional experiences.

13.3. Family gatherings: Hold family gatherings to unite loved ones and spend valuable time together.

13.4. Express emotions (thankfulness and love): Timely express love, gratitude, and care for others to foster warmth and support.

13.5. Reconciliation and farewell (apology and farewell): Address unresolved issues and strive for reconciliation. Arrange special activities or ceremonies for a meaningful farewell.

The importance of relationships becomes even more pronounced during palliative care. Establishing a warm and supportive environment helps alleviate psychological pressure.

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Chapter 22

Matters Family Members and Caregivers Should Understand and Assist With

1. Introduction

In palliative care, the support and involvement of family members and caregivers not only contribute to high-quality care but also provide the patient with additional love and comfort. Through the assistance strategies provided in this chapter, family members and caregivers can become indispensable members of the palliative care team, creating a warm, respectful, and loving environment together.

2. Matters family members and caregivers should understand and assist with

2.1. Learning care techniques

Family members and caregivers should actively learn relevant care techniques during the patient's palliative care period. This includes assisting with turning the patient, ensuring comfort in their positioning, and maintaining personal hygiene. With professional guidance, they can provide the necessary support more effectively, ensuring the patient feels comfort and love during their final days.

2.2. Assisting with pain management

Family members and caregivers should understand the patient's pain levels and assist the medical team in implementing an appropriate pain management plan. This includes administering opioids on schedule, adjusting body positions to alleviate discomfort, and providing psychological support.

2.3. Assisting with medication management

During palliative care, family members and caregivers should ensure the patient takes medications on time and monitor for possible side effects or adverse reactions. Maintaining communication with the medical team is essential to ensure the correct use of medications.

2.4. Providing oral care and personal hygiene

Good oral care and personal hygiene can maintain the patient's comfort and dignity. Family members and caregivers should assist with oral hygiene, changing clean clothes, and ensuring the patient's overall physical condition is well-maintained.

2.5. Effective communication with the patient

Effective communication is a crucial part of palliative care. Family members and caregivers should maintain good communication with the patient, listen to their needs and wishes, and ensure they receive appropriate support in their final stages of life.

2.6. Respecting the patient's wishes

Respecting the patient's wishes is an important principle in palliative care. Family members and caregivers should understand and respect the patient's desires, including medical treatment choices and end-of-life arrangements, to ensure the patient's dignity and respect in their final days.

2.7. Providing emotional support

Both patients and their families may face emotional challenges during palliative care. One role of family members and caregivers is to provide emotional support, understanding the patient's emotional needs, and offering warmth, comfort, and reassurance. Through careful companionship and considerate care, they can help the patient navigate emotionally difficult times.

2.8. Encouraging patient self-expression

Family members and caregivers should encourage patients to express their thoughts and wishes and actively participate in discussions about medical choices and end-of-life arrangements, enhancing the patient's autonomy.

2.9. Maintaining a comfortable living environment

Family members and caregivers should ensure that the patient's living space is clean and quiet, considering the patient's personal preferences, such as music and lighting, to create a comfortable and peaceful atmosphere.

2.10. Providing appropriate nutritional support

The nutritional needs of patients may change during palliative care. Family members and caregivers should pay attention to the patient's nutritional status, assist in providing suitable diets, and adjust the manner of food provision, such as offering easily chewable and swallowable food, to ensure the patient receives adequate nutritional support.

2.11. Arranging visits from friends and family

Family members and caregivers should facilitate good communication between the patient and their friends and family, arranging visits to the patient. This helps the patient feel loved and supported and provides opportunities for friends and family to share precious moments with the patient.

2.12. Assisting with the four paths of life in palliative care

The four paths of life in palliative care are expressing love, gratitude, apologies, and farewells. Family members and caregivers should support the patient and their family in expressing love and gratitude, making apologies, and saying farewells, helping the patient face the end of life with peace.

3. Conclusion

The role of family members and caregivers during the patient's palliative care period is multifaceted. Beyond providing practical care, they also need to offer emotional support, ensuring the patient spends their final days in an environment filled with dignity and love.

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