The Chinese University of Hong Kong
The Nethersole School of Nursing
CADENZA Training Programme

CTP 003

Enhancing quality at end-of life

Web-based Course for Professional Social and Health Care Workers

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Role of Rehabilitation in Palliative Care

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Chapter Outline

1. The relationship between palliative care and rehabilitation
2. The paradigm change of therapy practice in palliative care
3. Attributes of rehabilitation in palliative care
4. Establishing rehabilitation goals in terminally ill patients
5. Rehabilitation team in palliative care

Introduction

- *"The concept of rehabilitation may seem paradoxical in palliative care, especially for patients with an advanced illness who are approaching death."* *(Doyle et al, 2004)*

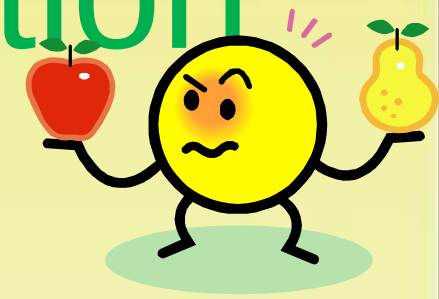
Do you agree? What is your opinion?

Introduction

- Rehabilitation in palliative care has received little attention, and there is scarce data to support its efficacy in terminally ill patients.
- However, clinical experience suggests that the application of the fundamental principles of rehabilitation medicine is likely to improve their care.

(Santiago-Palma & Payne, 2001)

The relationship between palliative care and rehabilitation



You matter because you are you and you matter until the last moment of your life. We will do all we can not only to help you to die peacefully but also to live until you die. (Saunders, 1976)

Definition

Palliative Care

An approach that *improves the quality of life* of patients and their families facing the problems associated with *life-threatening illness*, through the *prevention and relief of suffering* by means of early identification and impeccable assessment and treatment of pain and other problems, *physical, psychosocial and spiritual*. (WHO, 2011)

Rehabilitation

Rehabilitation of people with disabilities is a process aimed at enabling them to *reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels.*
Rehabilitation provides disabled people with the tools they need to *attain independence and self-determination*. (WHO,2011)

The role of rehabilitation in palliative care

- Rehabilitation is helping the person to be as independent and active as possible.
- The WHO identified palliative care as supporting patients to live actively until death.

Mackey suggests enabling a patient to retain some independence might enhance *quality of life* and assist in maintaining *self-identity.*

Thus, rehabilitation becomes an essential component of palliative care.

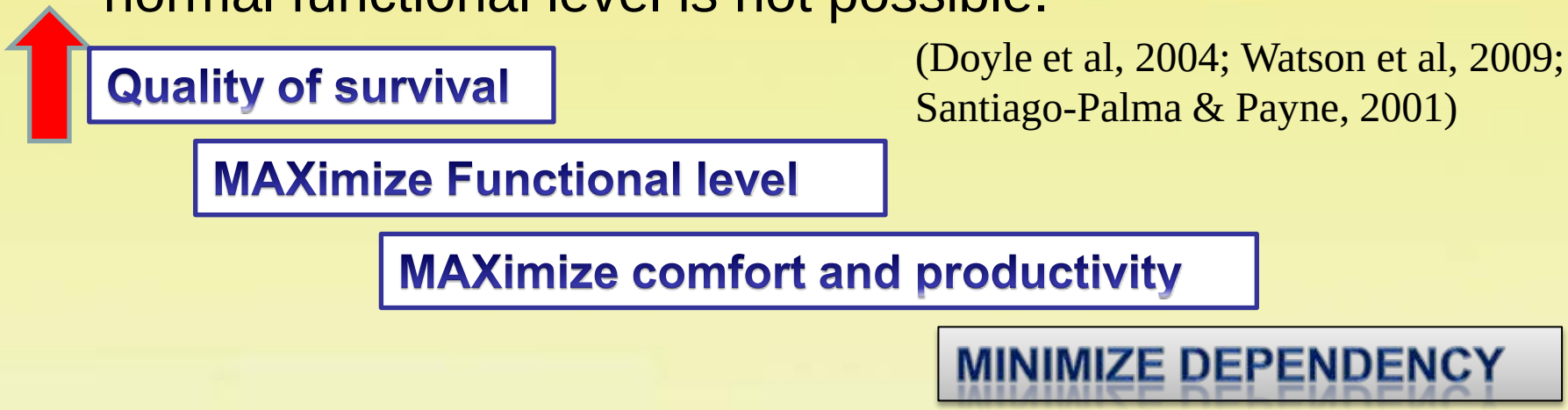
Palliative care and rehabilitation

- Palliative care and rehabilitation share *common* goals and therapeutic approaches.
  - Aims to improve patients' ***level of function and comfort***, taking into consideration the medical, physical, social and psychological status of the patient.
  - Both are ***symptom-oriented specialties.***
  - Includes ***both families and patients*** in treatment and decision planning.

(Santiago-Palma & Payne, 2001)

Rehabilitation in palliative care

- Aims to *maintain or improve the quality of survival in physical, psychological, social, vocational and spiritual terms* by a maintenance and compensatory approach so that patients' lives will be as *comfortable and productive* as possible and they can *function at a minimum level of dependency* regardless of life expectancy, or even if a normal functional level is not possible.



(Doyle et al, 2004; Watson et al, 2009; Santiago-Palma & Payne, 2001)

CASE SCENARIO

- Mr. Wong is 78 years old and has been living alone since the death of his wife 2 years ago. He has one son who lives 2 hours' drive away and visits at the weekend. James has chronic obstructive airways disease and has been diagnosed with an advanced lung tumour for which he has received radiotherapy to help to improve the symptoms. His family doctor is working with Mr. Wong to monitor his illness. His ongoing concerns include breathlessness, loss of appetite and low mood, due to his illness and social isolation.
- You have been visiting on request as his district nurse. He has a supportive neighbour, but she has been away on holiday for the last week. You have been contacted by his son, as Mr. Wong has fallen and appears to be getting weaker. His son is concerned that Mr. Wong may not cope at home and is asking for him to be assessed for placement in a nursing home, although Mr. Wong has always resisted this idea, saying that he wants to die at home surrounded by his memories.

Consider the following questions:

- Is this patient being supported as fully as possible?
- Are all steps being taken to maximize his potential?
- Could any other members of the team/other services be of help?
- What could be done differently?

(Foyle, L. & Hostad, J. 2007)

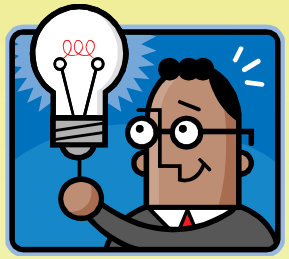
Whether the rehabilitation philosophy is alive in your practice?

Consider the following questions (***Adapted form the National Council for Hospice and Specialist Palliative Care Services. 2000, p.12)***

- Is rehabilitation prioritized as an important part of cancer and palliative care education in your locality?
- How do you encourage clinicians to address the rehabilitative needs of their patients?
- What teaching strategies do you employ for each cancer and palliative rehabilitative care?
- How might you develop and expand these in the future?
- Who could you work in partnership with to provide rehabilitation education?
- Could you work in partnership with others to provide rehabilitation?

(Foyle, L. & Hostad, J. 2007)

How could rehabilitation be appropriate or helpful to people with a deteriorating condition which is incurable?



Rehabilitation and Palliative Care CASE STUDY

- Assessing for seating for Mandy, aged 15 years: she had a mucopolysaccharide disease and had limited movement, a profound developmental delay, and although unable to speak she could communicate her pain and discomfort, as well as happiness. The community occupational therapist (OT) carried out a joint assessment with the hospice OT. The community OT was intent on a correct sitting position with 90 degrees at hips and knees, with equal weight distribution at hips and buttocks. This position could not be maintained, as Mandy had pain at her left hip (osteochondrities) and as a result would alter her position into extension at her left hip and knee, twisting her body as she did so. Mandy's pain relief was effective but she consistently avoided pressure on this area, which her mother thought might be habitual rather than due to pain,. The OT considered ways in which the correct position might be maintained, although they would restrict Mandy's' movement.
- The hospice OT was looking for the optimum comfortable sitting position and was guided by Mandy rather than a prescribed sitting position. This resulted in a chair which was padded, and could be altered easily into different positions, including tipping backwards and extending the back and seat with lower leg supports and footplate to relieve pressure on sitting. The community OT remarked, 'This isn't the chair or position I would ordinarily prescribe." The hospice OT said, "No, but this isn't an ordinary situation."*(Boog & Tester,2008)*

•What is your view on this scenario?
•What are the possible considerations in the assessment process for the most suitable seating system?
•Could you figure out the difference and similarities between the viewpoints of the community OT and hospice OT?

•The assessment was extensive and considered all aspects, including scoliosis and pressure relief, Mandy's preferences for sitting, and her comfort.

The paradigm change of therapy practice in palliative care



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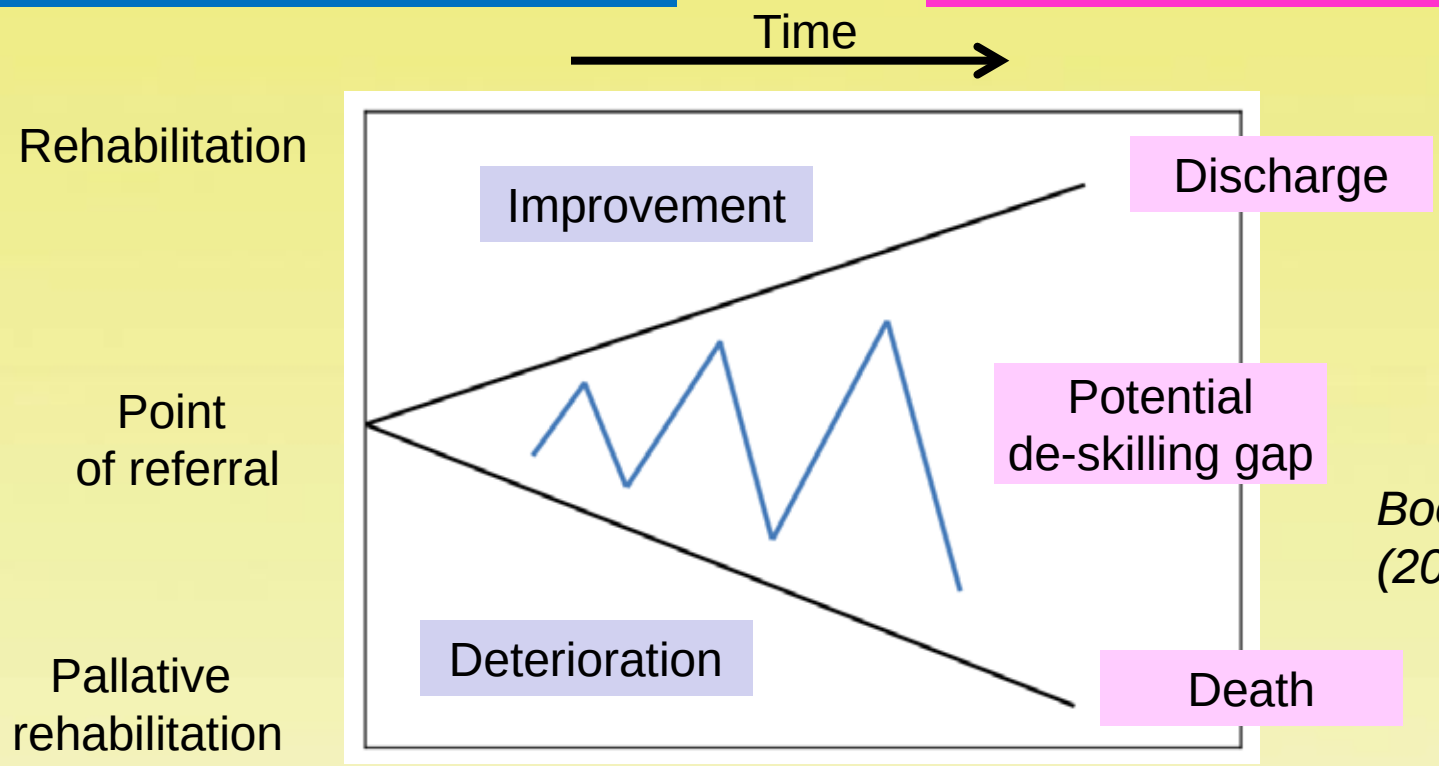
A comparison of usual and palliative rehabilitation

Usual rehabilitation model of improvement and discharge

VS

Palliative rehabilitation when a person deteriorates and dies



Boog & Tester (2008)

Do you encounter any difficulties or experience real situations concerning the paradigm shift in clinical practice?

The concept of "rehabilitation in reverse"

‘Rehabilitation in reverse’?

- For example, it may be that an initial goal for a patient is *to walk to the bathroom* independently.
- As the patient's condition deteriorates, this goal may change *to walking to the bathroom with a walking aid and a carer.*
- Finally, being *able to transfer safely onto a commode* at the side of the bed.

(Baldwin & woodhouse, 2011)

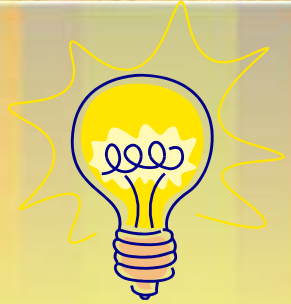
"Rehabilitation in reverse"?

- Another example
  - A patient has a brain tumor and is unsteady. He has been *walking without a cane.*
  - Now you have to *teach him how to use a cane* and *teach family members to assist with balance*.
  - A week or two later, you need to *fit him with a walker and teach him to use it.*
  - A month later, you are *teaching transfers* from bed to a wheelchair.
  - And one week later you might be *positioning for pressure relief.*

‘Rehabilitation in reverse’

- While progress appears to be in reverse and the general trend is downwards, the patient is still given *positive rehab goals* to achieve. The aims are to *ensure safety* and *maintain quality of life* for as long as the condition allows.
- As the patient‘s health is declining through out each phase of the dying process, there is always some level of new or adapted skills and abilities that you can provide to the patient, as well as the caregivers, to maximise functional independence and safety.

  (Pizzi & Briggs, 2004)
- Patients must be enabled to maximise their remaining functional abilities in order that they are able to work towards any *unfulfilled goals*.
- By ensuring that goals are *small and achievable,* it is often possible to measure a positive outcome of therapeutic intervention.



The paradigm change

- Rehabilitation in palliative care needs to be reframed by the therapist, as patents may not have any demonstrable improvement in skills.
- The therapist cannot measure therapy outcomes in terms of progression in strength and ability.
- **Outcomes of therapy need to be measured in terms of enablement, support and quality of life as they relate to the individual and the individual's family.**
- In rehabilitation of terminally ill patents, maintaining a balance between optimal function and comfort becomes a key issue.

(Santiago-Palma & Payne, 2001)

The paradigm change

- The goals of rehabilitation and palliative care, at first glance, appear incompatible.
- While rehabilitation cannot eliminate illness's assaults on functional autonomy, it can certainly attenuate and decelerate them.
- In rehabilitation, functional decline is not experienced with helplessness.
- This is an important time (dying) to provide support to enable people to complete the tasks that are meaningful to them, which can include the physical, emotional, social, and spiritual.

(Cheville, 2001; Santiago-Palma & Payne, 2001)

Attributes

of the rehabilitation in palliative care

The key attributes of rehabilitation in palliative care

1. **Interdisciplinary approach to care**
   - Ø **with collaborative working and partnerships**
   - Ø **effective co-ordination and liaison across boundaries to promote seamless care**
   - Ø **education and commitment of all staff to enable consistency of approach**
2. **Maximizing comfort and minimizing dependence**
   - Ø **enabling adaptation to current situation, coming to terms with illness and changed circumstances**
3. **Looks at restoration of quality of life**
   - Ø **facing up to uncertainty and loss**
   - Ø **helps patients gain opportunity, control, independence and dignity**
4. **Adopts a compensatory approach with a focus on problem solving and the promotion of coping strategies**
5. **No set formulaic protocol**
   - Ø **as people are different and have unique views on their quality of life**
6. **Responds quickly**
   - Ø **to help patients adapt constantly to their illness**
   - Ø **anticipation by the team of potential deterioration, allowing time to address relevant issues with the patient and/or family and carers**
7. **Takes a realistic approach to goal setting**
8. **Individual pace**
9. **Is an attitude as well as process**
10. **Education is the major component**

(Watson et al, 2009; Doyle et al, 2004; Santiago-Palma & Payne, 2001)

Successful palliative rehabilitation depends on

- attitude and approaches adopted by staff
  - encourage independence and promote sense of pride and not being a burden
- speed of team response
- setting of realistic goals
- adapting constantly to changing circumstances
- supporting patients and carers through change

(Watson et al, 2009)

Usual application of the principles of rehabilitation

- Fatigue and dyspnea management
- Pain management
- Psychological symptom management
- Level of ambulation/ mobility
- Functional independence in activity of daily living
- Safe and comfortable positioning
- Lymphoedema management
- Breathlessness management
- Stress management
- Grief interventions
- Anxiety and depression management

(Foyle, L. & Hostad, J. 2007; Santiago-Palma & Payne, 2001)

Goal Setting

Goal Setting

- Important to review rehabilitation goals on a regular basis due to the dynamics of terminal illness.
- Discussion of how goal setting should evolve across the trajectory of the terminal illness.
- Assessing patients rehabilitation needs to consider systematically what restorative, supportive, preventative and palliative goals are appropriate.

The principles of goal setting

1. The patient and family must play an active role in establishing the goals.
2. Support the patient in attaining their chosen goal.
   - Ø For some individuals, the focus may be their comfort, ease, and solace.
3. Goals need to acceptable within single disciplines, between disciplines and most essentially to the patients.
4. Understand the implications of a prior prognosis; patients within palliative care settings are deteriorating and techniques need to be individually tailored to the rate of clinical deterioration.
5. Preserve each phase of the patients' independence as long as possible to reduce the burden of care on the caregivers.
   - Ø Recognise the patient's functional needs.

(Doyle et al, 2004)

The principles of goal setting

6. Realistic and take into consideration the stage of the disease, the patient's medical status, cognition, and prognosis, and the site of planned discharge.
7. The ability to determine priorities will be influenced by prognosis, and an ability to predict the most likely course of a patients' illness within a realistic timeframe is very important.
8. The goals must remain flexible and sensitive, reassessed, revised and adjusted continually in parallel with the exacerbations and remissions of disease and symptoms.
   - Ø Set regular review dates. Some review dates will be very short; in the later stages of the disease trajectory the goals may have to be reassessed on a day-to-day or even hour-to-hour basis.
9. Goals that foster insight and understanding may be more important than those that facilitate physical independence.
   - Ø Address the patient's concerns, special needs, and psychosocial and spiritual needs.

(Doyle et al, 2004)

Four categories of rehabilitation goals

- Restorative rehabilitation
- Supportive rehabilitation
- Preventative rehabilitation
- Palliative rehabilitation

(Cheville, A.L. 2005)

Four categories of rehabilitation goals

- Restorative rehabilitation
  - The effort to return patients to their premorbid functional status when little or no long-term impairment is anticipated.
  - *Can you think of any examples?*

Restorative rehabilitation examples

1. Impairments associated with cancer-related surgeries such as mastectomy and auxillary lymph nod dissection are common considerations.

Ø Following these procedures, breast cancer patients should recover full shoulder range of motion and upper extremity strength. If long-term deficits occur, with restorative rehabilitation patients are expected to recover to their premorbid levels of flexibility and strength. (Cheville, A.L. 2005)

Restorative rehabilitation examples

2. Interval aerobic conditioning following one marrow transplantation. Bone marrow transplant patients generally experience decline in their oxidative capacity in association with transplantation.

Ø With the initiation of an appropriate restorative rehabilitation programme involving structures and progressive aerobic conditioning, they can recover to their premorbid level of aerobic fitness.

(Cheville, A.L. 2005)

Four categories of rehabilitation goals

- Supportive rehabilitation
  - Attempts to maximise function after permanent impairments caused by cancer and/or its treatment. Cancer patients often sustain irremediable impairments; however, those need not produce significant disability or handicap. Supportive measures enable patients to circumvent the impairment and preserve their mobility and independence. (Cheville, A.L. 2005)
  - *Can you think of any examples*?

Supportive rehabilitation examples

1. Following surgical limb salvage, pelvic and lower extremity biomechanics are adversely affected. A rehabilitation programme geared toward the restoration of proprioception, balance, and normal ambulatory patterns will minimize lasting gait abnormalities.

(Cheville, A.L. 2005)

Supportive rehabilitation examples

2. Cognitive remediation following the resection or irradiation brain tumours. Many patients experience cognitive deficits following definitive treatment, but remediation programmes allow precise definition of these deficits and the provision of compensatory strategies to minimise their functional impact.

(Cheville, A.L. 2005)

Supportive rehabilitation examples

3. Physical therapy for head and neck cancer patients following neck dissection and sacrifice of cranial nerve XI. Therapeutic strengthening and flexibility activities can do much to mitigate long-term shoulder dysfunction. Many patients never experience complete reinnervation of the trapezius muscle, However, with strategic strengthening of alternate shoulder elevators and retractors, patients need not develop significant associated disability.

(Cheville, A.L. 2005)

Four categories of rehabilitation goals

- Preventative rehabilitation
  - Attempts to preclude or mitigate functional morbidity caused by illness or its treatment. This is perhaps the most unappreciated yet powerful strategy. It is always easier to preserve strength, flexibility, and aerobic conditioning than to restore them once compromised. For this reason, patient education in appropriate preventative approaches helps to reduce long-term functional morbidity.
  - *Can you think of any examples?*

(Cheville, A.L. 2005)

Preventative rehabilitation examples

1. After radiation therapy, some degree of soft tissue and muscle contracture generally occurs following radiation therapy. If patients are instructed in appropriate muscle stretching at the time of radiation therapy, these conditions can be minimised.

(Cheville, A.L. 2005)

Preventative rehabilitation examples

2. Protection of insensate skin secondary to chemotherapy-related peripheral neuropathy is another example of preventive rehabilitation. For many stage IV cancer patients receiving serial neurotoxic chemotherapies, proprioceptive and sensory impairment is severe, particularly among elderly cancer patients. If these patients are provided with appropriate orthotics and instructed in close monitoring of dermal integrity, decubitus ulcers and other adverse effects can be prevented.

(Cheville, A.L. 2005)

Four categories of rehabilitation goals

- Palliative rehabilitation
  - Its primary goal is the reduction of dependence in mobility and self-care activities in association with the provision of comfort and emotional support.

    (Cheville, A.L. 2005)

  - *Can you think of any examples?*

Palliative rehabilitation examples

1. Enabling patients to remain independent with bowel and bladder management is a prime goal. Fecal and urinary incontinence, in particular, engender psychological distress. Through provision of assistive devices and instruction in compensatory strategies, patients maintain personal hygiene until the extremely advanced stages of disease.
2. Education in energy conservation approaches is also helpful. Patients learn to pace themselves and make ergonomic modifications.
3. If mobility is significantly threatened, provision of aids such as wheelchairs or scooters to ensure continued community integration and to prevent social isolation is recommended.

(Cheville, A.L. 2005)

Rehabilitation team in palliative care

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Rehabilitation team in palliative care

- Interdisciplinary group.
- Role definitions are purposefully blurred.
- The boundaries are widely overlapping.
- Authority is shared, as is decision making.
- Innovation is encouraged wherever necessitated by patient need and circumstance.
- In order to achieve high level of fluid teamwork , a high level of communication must be maintained which requires considerable maturity, trust and intimacy.
- The team members often engage in a high level of sharing including professional knowledge as well as personal emotional feelings triggered by patient and family during the process.

Rehabilitation team in palliative care

- The patient, family and carers
- Rehabilitation medicine specialist/physician
- Rehabilitation nursing staff/case manager-ward and community-based
- Occupational therapist
- Physiotherapist
- Speech and swallowing therapist
- Social worker
- Chaplain/pastoral carer
- Rehabilitation psychologist
- Prosthetist/ Orthotist
- Complementary therapists
- Dietician
- Other specialists, according to need

(Watson et al, 2009)

Role of the members:

The patient, family and carers

- All treatment must be given with the patient's consent and in accordance with his/her wishes.
- The family and carers have an important role in the overall care for the patient and their opinions should be included when formulating plans for treatment and care.

(Fine, P.G. ,2008)

Role of the members:

Physician

- Reviews medical history; examines patient when indicated and certifies for palliative care.
- Works with whole team to develop plan of care and authorises medical orders.
- Manages pain and other distressing symptoms.
- Palliative physician attends interdisciplinary team meetings and confers with attending/referring physician as needed.

Fine, P.G. (2008)

Role of the members:

Nursing staff/case manager-ward and community-based

- Communicates with physician, family and patient to develop initial plan of care.
- Ensures that medical orders and durable medical equipment are in place and trains/instructs nonprofessional caregivers.
- Coordinates plan of care, providing direct patient care and directs other nurses, aides, and volunteers.
- Manages resources.
- Establishes rapport and trust with patients, family, and attending physician – furthers discussions about advance care plans and end of life decisions.
- Coordinates input at interdisciplinary team conferences.

(Fine, P.G.,2008)

Role of the members:

Social worker

- To strengthen people in managing and dealing with emotional, psychological and social consequences of what is happening to them.
- To enable people to make the best possible use of welfare services and family, social network and community resources that will help them.
- To develop community organisations and groups, provide mutual help and support for people in dealing with the problems in their lives.

(Fine, P.G.,2008)

Role of the members:
Chaplain

- Addresses cultural needs, including the need to be in an environment that reinforces the familiar –this takes in language, food, dress, family and social structure, customs, etc.
- Addresses religious needs, including the need for support to practice sacred rituals and hold certain beliefs and will require provision for prayers, sacraments, holy books, religious artifacts (e.g., prayer mats, rosary beads).
- Addresses pastoral needs, including the need for support at life's critical moments –relationship formation, illness, death, e.g., funeral, marriage, etc. –typically addressed with reference to particular beliefs or values, religious or otherwise.
- Addresses spiritual needs, including the need for a sense of 'well-being', which is often nurtured by being well related to one's self, others, and one's source of ultimate meaning. Some chaplains refer to this as 'psycho-spiritual need'.

(Watson et al, 2009)

Role of the members:

Occupational therapist

- **Assistance with psychological adjustment and goal-setting related to loss of function.**
- **Retraining patients in personal and domestic activities that are necessary for daily living.**
- **Assessment and prescription of wheelchairs and seating and pressure care needs.**
- **Splinting to prevent deformities/ contractures and control pain.**
- **Home assessments and referral to community agencies for assessment and provision of equipment.**
- **Lifestyle management/investigating hobbies and leisure pursuits and roles within family life.**
- **Relaxation techniques.**
- **Education of patients, carers, students and health care professionals.**
- **Key role in home discharge plan to enable the patient and carers to cope as safely, comfortable, and confidently as possible at home.**
- **Other specific roles in the management of complex symptoms like breathlessness and fatigue.**

(Watson et al, 2009)

Role of the members:

Physiotherapist

- Optimizes mobility and endurance.
- Gait re-education, stair climbing, transfers and provision of walking aids.
- Relaxation training.
- Assessment of pressure risk and necessary provision.
- Symptom control including pain management, lymphoedema management and respiratory care.
- Maintenance of joint range and muscle power.
- Education of patients, carers, students and health care professionals.
- Manual handling advice to professionals and carers.
- Advice on pacing energy conservation.

(Watson et al, 2009)

Role of the members:

Speech and swallowing therapist

- The overall aim is to help people with communication difficulties make the most of their abilities for as long as possible.
- To help people having difficulty in eating and/or drinking to swallow as safely as possible and to inform the medical team if the swallow appears unsafe.
- According to communication/swallowing diagnosis (i.e., nature, severity) and management planning, four areas of intervention including:
  - 1)direct therapy e.g., speech exercises, voice therapy, communication aid training, swallowing postures
  - 2)indirect therapy/advice e.g., strategies to maximise communication or to maintain safe oral intake
  - 3)counselling e.g., patient and/or family regarding future speech changes
  - 4)education e.g., in-service training (general or patient-specific)

(Watson et al, 2009)

Role of the members:
Psychologist

- Helping staff formulate a problem in a psychological way.
- Teach specific skills and interventions, for example relaxation and cognitive behaviour therapy.
- Supervise specific cases and encourage the use of specific psychological interventions.
- Provide individual or group counselling and individual psychotherapies.
- Joint working with other team members.
- Support team decision-making and cohesiveness as well as the team members.

(Watson et al, 2009)

Role of the members:
Dietician

- Assess a patients' nutritional status.
- Elicit the patients' goals regarding nutrition.
- Provide specialized nutritional advice at diagnosis, during treatment and in the palliative phase.
- Advice on food preparation/fortification/supplementation as appropriate.
- Relax dietary restrictions if possible, i.e., for patients with diabetes and hypercholesterol stages.
- Recommend and calculate feeding regimens to suit an individual patient's requirements, using enteral or parenteral access.
- Provide psychological and emotional support.
- Listen to patients' fears.

(Watson et al, 2009)

Role of the members:
Complementary therapists

- Complementary treatments are used alongside conventional treatment.
- Common examples are art therapist, music therapist.

Conclusion

Palliative rehabilitation

- WHO identifies palliative care as supporting patients to live actively until death.
- In this context, rehabilitation becomes an essential component of palliative care rather than an additional luxury.
- Future research on the rehabilitation of terminally ill patients should focus on better understanding the role of rehabilitation and defining appropriate interventions.

Rehabilitation in palliative care needs

- To be patient-led rehabilitation.
- Goals set by patient, their carers and the therapist.
- Realistic, achievable, short-term goals.
- Goals constantly revisited as condition progresses.
- Emphasis on enabling rather than restoration of function.
- To maintain hope without giving false expectations.
- Interdisciplinary team.

(Baldwin & woodhouse, 2011)

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