Physiotherapy in palliative care – a clinical handbook

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Foreword

Palliative care is good care at the end of life with the goal to give the best possible quality of life to patients and their family. We who are working in palliative care think this is obvious. But what are the characteristics of good care at the end of life and what are the criteria? How can we know that what we do for patients and their families is most adequate and even most cost effective?

Most patients at the end of life are cared for within primary health care, nursing homes and in hospitals. Many are also cared for within specialized palliative care, in hospices and palliative care units as well as in specialized home care. Specialized palliative care is team-based and consists of physicians and nurses but often also include assistant nurses, physiotherapists, social workers and occupational therapists and sometimes also a priest, a deacon and a dietician.

The physiotherapist’s special competency in the palliative team emerges clearly in this clinical handbook which firstly is aimed at physiotherapists caring for severely ill and dying patients. But the handbook will also provide important information about physiotherapist work in palliative care for other professions. As far as we know this is the first Swedish textbook on physiotherapy in palliative care.

Most of the symptoms and problems physiotherapists meet in clinical everyday life are represented in the handbook. Knowledge, both scientific as well as the experience-based, is described and are the basis for suggested interventions and treatments.

We know thorough scientific studies for common physiotherapeutic treatments are lacking, especially in palliative care. An inventory of the most important pitfalls in knowledge should be the basis for planning future research in physiotherapy in palliative care.

We hope this handbook will be useful for the education of physiotherapists as well as a reference book for physiotherapists meeting and treating patients at the end of life.

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Introduction

Patients in a palliative phase of their disease are treated in all health care settings, e.g. specialized palliative home care and in-care units, acute clinics, nursing homes and also in primary care, and many patients are cared for at home. Most physiotherapists will therefore have contact with these patients and their family, even though most of the physiotherapists will not work in specialized palliative care. This means that students going through basic training to become a physiotherapist need knowledge that can support patients in a palliative phase of their disease.

In December 2006 the Swedish Board on Health and Welfare published a report on “End of life care - the Board on Health and Welfare’s judgment of the development in communities, counties and regions.” (1) In the report it was stated “the importance of palliative care being more noticed today when curricula in medical faculties and universities and other educational facilities are concluded.”

A survey had been distributed to find out the amount of education in palliative care that was offered in the basic training for all health care professionals in Sweden. In the report from the Swedish Board on Health and Welfare it was clear that the difference was huge - from a few hours to a few weeks. At the time for the survey no physiotherapy education had palliative care in the curriculum in the basic education. We have found chapters describing physiotherapy in various books on palliative care. There was no educational material on physiotherapy in palliative care.

This clinical handbook in palliative care for physiotherapists aims at physiotherapists who have basic knowledge in physiotherapy but lack the knowledge and experience of working with patients in a palliative stage of their disease. The base of the handbook is 25 years of collected experience from palliative physiotherapeutic work at the Stockholms Sjukhem Foundation, a work mainly focused on patients with cancer in a late stage of the disease.

The statistics that were produced during the physiotherapeutic activities in the spring and fall of 2006 is the foundation for the book. All physiotherapeutic procedures were recorded as well as the time used for every single activity. Physical activity like mobilizing and exercises was used most frequently followed by lymphatic therapy, massage and TENS-treatment. Later a literature study was made to describe the scientific evidence for the methods used.

Stockholms Sjukhem Kungsholmen has a specialized palliative section with two in-patient units and specialized home care. It used to be a palliative unit only for patients with a cancer disease.
but today the section includes care for patients with other chronic illnesses, like cardiovascular and lung diseases, COPD but also neurological diseases and motor neuron diseases like ALS. But the focus in this handbook is on patients with cancer in a late stage of their disease as this is our biggest source of experience. Most can be transferred to patients with other diagnosis in a palliative stage.

The comments above are the basis for this clinical handbook which we hope will be used for the benefit of the patient. The handbook will be revised and developed over time.

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Definition of palliative care

The word palliative derives from the Latin word “pallium” and means cloak, something in which you wrap yourself or another human being. The cloak symbolizes the care of the dying person.

Palliative medicine includes care of and research on patients with incurable diseases and a short expected survival. The goal of the treatments is to give the best possible conditions to the best possible quality of life for the patient and their family for the rest of the time.

WHO’s definition of palliative care is an approach that improves the quality of life of patients and their families facing the problem 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. Palliative care: provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness an in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. (2)

Palliative care is total care considering the physical, psychological, social and existential needs. The care could be said to be built on the four corner stones, symptom control, team work 24-hours a day, continuity and support for the family. Family, as defined by the patient, can be the family, a partner and close friends.

The team can consist of different professions e.g. physician, nurse, assistant nurse, physiotherapist, occupational therapist, social worker and dietitian. To be able to give a good holistic care there is a need for the whole team. Access to a priest/deacon is also useful. By using the specific knowledge of the different professionals the over view of the patient’s...
problems increase and the possibility to aid the patient with better symptom relief and a better quality of life improve.

Palliative care can be divided into an early and a late phase. In the early phase the cancer has spread but is responding to the tumor specific treatment. The goal is then quality of life and to prolong life. Patients may sometimes live several years with the disease, for example with breast- or prostate cancer. In the late phase the tumor specific treatment has stopped and this phase is often just a few weeks or sometimes months. The goal for this phase is quality of life and not life prolongation.(3) Also during this phase radiation therapy can be given to relieve pain.

Palliative care has its roots in the modern hospice movement initiated by Dame Cicely Saunders. She was an English nurse, social worker and later physician who in her work found that the patients did not just have physical pain but also psychological, social and existential problems. She founded St Christopher’s hospice in London 1967. Apart from being the first hospice it was also the first educational and research unit in this subject. The goal was to improve the condition of life of the dying person and the family. Cicely Saunders work inspired others to follow and today there are followers throughout the world including Sweden.

**The quality of life of the patient**

When cure is unlikely the patient can get help to maintain and if possible improve the quality of life. The physiotherapist has an important role to complement palliative care treatment with a variation of symptom relief activities and thus keeping/improving the patients bodily functions.

When a person is seriously ill the awareness of how important the physical body is for all experiences and emotions becomes obvious. The state of the body decides what the patient can take part in and do in everyday life.

The state of the patient can vary considerably from day to day. Patients tell how stressful it is to see the body change and how the illness has made them more vulnerable as to how their body is treated and cared for by others.(4) To be touched on the body in an emphatic way can give satisfaction and confirmation.

When the illness progresses the physiotherapeutic contribution can still be important and the contact with the patient is of course easier if there has been an earlier relation with the patient. Examples can be passive movements, massage and showing positions of rest. Advice and support to families and personnel can be given.
**Palliative rehabilitation**

Patients live with their illness longer today in a palliative stage thanks to the improved medical treatment. Many of these patients get chronic functional impairment caused by the disease or by medical or chirurgical treatments. This makes rehabilitation and physiotherapy very important. (5)

Palliative rehabilitation is a comparatively new concept now more often used in palliative care, even if it is described already in the 1960s. The aim of having a rehabilitative approach when treating patients in palliative care is to set the goal for treatment so that the patient can keep or improve functions and reduce the consequences of the disease for as long as possible. To lose functions brings a changed view of one self and less possibility to independency which is very stressful for the patient as well as for the families. The goal for the physiotherapeutic treatment is to keep as much independency as possible to make the important activities for the patient easy. (6)

To be able to plan the best physiotherapy treatment for the patient, to know about the patient’s primary cancer diagnosis, the localization of the tumor and possible metastasis is important. The prognosis is of importance as well as ongoing medical treatment and if there are other diagnoses. Any contradictions for physiotherapeutic treatments and if the patient is aware of his/hers illness, is also relevant information. (7)

**The physiotherapist role in palliative care**

The overall aim for physiotherapy in palliative care is to help the patient reach the best possible quality of life for the rest of the patient’s life, to look after the physical as well as the psychological side for as long as possible. When the patient has an incurable disease the patient, families and health care personnel often accept a loss of function as inevitable and do not make use of functions still intact. (8) The physiotherapist aiming at rehabilitation and focusing on the physical capacity of the human body has an important role to play and to remind and activate the functions still intact.

To see the physiotherapist is often positive and gives the patient a possibility to pause in the knowledge that death is near – a kind of time and room to breathe. (4) With a cancer disease the bodily changes are obvious and many suffer from changes in their appearance, limited movements and impaired functions. Many medical activities like injections, taking blood samples and inserting a catheter can be unpleasant and painful. The touch and skin contact that the physiotherapeutic treatment give to the patient is often one of the few positive bodily contacts that the patient experiences.
To work as a physiotherapist with very ill and dying patients means that you use common physiotherapeutic treatment methods but there is a need to know quite a bit about the patient’s disease as well as to have a different approach as the treatment goal is different when managing this group of patients. The goals must be short-term and flexible as they might need to change to comply with the changing condition of the patient. It may be necessary to make a renewed assessment every time you meet because the patient’s general condition can vary from day to day. You might need to work towards an unrealistic goal but this can be important for the patient to be able to handle his situation.

The physiotherapist can help decide the amount of activities that are realistic and together with the patient set out a goal. To minimize symptoms and optimize function, to maintain the function and to preserve the patient’s autonomy – are examples of treatment goals, if this is what the patient wants. (9) The patient, family or staff may need to be instructed in techniques to help maintain functions. (10) For instance to rise, to sit in the bed or to move between bed and wheelchair.

Palliative care is a total care and the physiotherapist must also consider the patient’s other wishes and needs besides the physical needs. To show empathy and listen to the patient in often very difficult situations is also an important part of the treatment. The patients have different needs and different ways of handling life-threatening problems and it is very important for the physiotherapist to be sensitive to the differences. It is also important for the physiotherapist to be able to accept the patient’s approaching death as a reality without taking away the patient’s hope.

It is not uncommon that the patients deny the seriousness of their situation and sometimes even deny the disease. It can be a way of handling the situation, a way of coping, to lessen the fear and anxiety for the outcome of the disease – death. Some patients vary between having a good understanding of their situation and a time later to talk about what they will do and how they will act when they get well. It can be difficult to find a way together with the patients to be honest and at the same time to let the patients have their defense mechanisms left.

**Assessment**

Clear physiotherapeutic goals are a prerequisite to be able to assess the activities. In an early palliative phase where the goal can be to exercise to regain the patient’s earlier function, balance and walking tests can be relevant assessment instruments.
When the patient is in a late palliative phase losing bodily functions is to be expected. The physiotherapeutic activities in palliative care are often about keeping the functions. Goals change when worsening occurs. Usual qualitative assessments of physical functions can then become a confirmation of deterioration and will not give the patients feeling of support, security and expectations. (9)

Patient Specific Functional Scale (PSFS) is an assessment instrument that grades the ability for the patient to do important activities. It is important that the patient feels involved in the physiotherapeutic activities and that it is positive. For physiotherapy in palliative care it is important to show the patients the resources they still have left.

Visual Analog Scale (VAS) Borg-RPE scale or Borg-CR10 scale can be used when you want to measure the patient’s feelings of the symptoms. The intensity can be measured before and after activity treatment. For a patient in a late palliative stage of the disease with difficulty to judge their symptoms, the scale can be used verbally or ask questions that can be answered with a yes or no.

**Base of knowledge**

All care and treatment, including the physiotherapeutic, should be built on knowledge and clinical experience. Physiotherapists today strive to work in an evidence based way which means integrating clinical knowledge, the patient’s unique situation and wishes with the best possible research evidence.

Evidence based care means a systematic and conscious effort to provide care built on the best available scientific evidence. Evidence here means the best available evidence, of effect or value of a treatment or other activity. The foundation for evidence based medicine is the systematic over view of existing research results. The Swedish Council on Health Technology Assessment – SBU has the mandate of the Swedish Government to comprehensively assess healthcare technology from medical, economic, ethical, and social standpoints.

Scientific assessment in health care aims to identify interventions that offer the greatest benefits for patients while utilizing resources in the most efficient way. SBU is currently using four levels to grade evidence.
Strong scientific evidence
Moderate scientific evidence
Limited scientific evidence
Insufficient or contradictory scientific evidence (10)

For the searching of articles the data bases MEDLINE, PEDro and Cochrane Library have been used. In the first place bigger studies and review articles have been chosen, and where these could not be found smaller studies have been used.

**Psychological aspects**

**Crisis**

To be hit by a life-threatening disease is a threat to the whole existence as well as to present well-being and future plans. It is against common social roles within the family and in working life. This causes a crisis with most people.

The way the crisis is handled depends on several factors like how long the patient has known about the disease, how he was treated when diagnosed and at what age the patient was diagnosed. It is also important to consider what phase of life the patient is in, how different situations have been handled before in life and what kind of social support there is.

When a patient is affected by a severe illness it often leads to a crisis for the family.

Patients in a late palliative stage have often been hit by recurrent threats and losses during their time of disease, for example when treatments have had no effect. This causes the patient to repeatedly get into a crisis situation. This often arouses strong feelings like rage, guilt, self-reproach, loneliness and sorrow.

**Worry / Anxiety**

The feeling of anxiety indicates that something unpleasant is about to happen. When the feeling of worry gets stronger it is called anxiety. This is a natural reaction to threat and severe stress and can show as fear, worry, anger and panic. Often bodily symptoms like dyspnoea, palpitations, sweating, vertigo, nausea and muscle tensions can become apparent. Restlessness and apathy can also be expressions of anxiety.
**Assessment:**

How severe are the worries or the anxiety?
The patient’s feelings of the severity of the symptoms can be estimated with a Visual analog Scale – VAS before and after activities.
Does the patient receive medication for his/her anxiety?
Is it possible to divert the anxiety?
What stage of disease is the patient in?
Judging if a physiotherapeutic activity can be of help for the patient should be done after consulting the rest of the staff.

**Treatment:**

By affecting physical symptoms like muscle tensions, that divert the thoughts, physiotherapy can ease symptoms of milder forms of anxiety.
Treatment alternatives can be relaxation exercises, massage and physical activities like walking.

The choice of treatment depends on the stage of the disease the patient is in. In an early palliative phase physical exercises and relaxation activities can be useful. In later stages soft massage can be useful.

The clinical experience of soft massage for anxiety patients is good. Patients in a late palliative stage receiving soft massage can feel satisfaction, get the feeling of confirmation and free from illness during the massage as well as immediately after.

There is a limited scientific documentation of how physical activity affects anxiety. A temporary relief of situational anxiety can be noticed after physical activity.

**Depression**

It is common for the patient to feel low-spirited and sad because life is coming to an end. When the low spiritedness becomes more severe the word depression is used. Depression is caused by biological, psychological and social factors. With a severe somatic illness several factors can trigger and affect depression.
Depression can be hard to diagnose as it is natural to be low-spirited when one is severely ill and many of the symptoms when depressed are common also when one is seriously ill. They can also be side effects of treatment.

Common symptoms when depressed are low spiritedness, anxiety, sleeping disorder, loss of appetite, restlessness, tiredness and concentration problems. (7)

Sometimes patients in an early palliative phase, who probably still have a long time to live but are sad because the disease makes them believe that death is imminent, become inactive and bed bound.

Except for medical treatment these patients need activating /mobilizing not to get secondary complications because they are inactive and if possible to improve quality of life for the time they have left.

**Assessment:**

The assessment if the patient is depressed should be done by a physician.
What palliative stage of the disease is the patient in?
How severe is the depression?
Is the patient capable of co-operating in physiotherapeutic treatment?
Does the patient want to?

**Treatment:**

For patients in an early or late palliative phase and who want and feel like taking walks, aquatic exercises or light fitness training can be useful.
The physical activity must be adapted to what the patient can handle, manage and want.

Physical exercise can have a positive effect on depression. Physical exercise is best when it is combined with medical treatment and consultation. (12)
Common problems for patients who have cancer in a palliative phase

Metastasis of the skeleton

Metastasis of the skeleton is the most common cause of pain for patients with cancer. Metastases of the skeleton can be seen with all kinds of cancer but most common with breast- and prostate cancer. It is also common with metastasis of the skeleton with lung- kidney and thyroid gland cancer.

The most common localization for metastases is the spine, skull bone, pelvis upper part the humerus and upper part of the femur.

Metastases of the skeleton often result in destruction of bone tissue – osteolysis – rather than the bone tissue becoming osteosclerotic and the skeleton will gradually deteriorate and become decalcified. The skeleton around the metastasis becomes very fragile and the risk for fractures increases. Radiation therapy is often used for pain and also to prevent pathological fractures and compression of the vertebrae or to lessen the compression of the spine. (13, 14)

Pathological fractures

A pathological fracture is a fracture that can occur without prior trauma to the skeleton which is fragile for example because of metastasis. In the extremities it is mostly femur and humerus that are affected. With a pathological fracture there is no normal fracture healing process. Surgical treatment can be needed to make the joint stable, pain free and functioning. Radiation treatment can be used to reduce the pain and increase stability.

The post operative mobilizing of the patient does not differ from mobilizing patients with other fractures, but there might be a different pattern of pain and the illness itself or the treatment can affect the patient’s general condition and be a hindrance to mobilization. (14)

It is common that patients who have had a pathological fracture in spite of the fact that they have received surgical treatment and can be mobilized, are very afraid of getting out of bed and standing on the leg. With information about the stability of the fracture, support and encouragement the patient can feel safe and dare to use the leg again, this way function can be regained and complications from lying in bed can be hindered.
Compression of the vertebrae affecting the spine

Metastasis of the vertebrae can cause problems when there is pressure on a nerve root and with compression of the spine. If there is a spontaneous fracture of the vertebrae the compression of the spine is often increased and could result in paralysis. The surgical treatment aims at lessening pressure on the medulla through cleaning the vertebrae or through a laminectomy after which the spine is stabilized with a splint. The most common symptom of compression of the spine is pain in the back where the metastasis is located. Pain can also radiate from the nerve root of the segment that is damaged. The pain follows the segment of the dermatome. Other symptoms like ataxia, reduction of feeling of sensitivity and of motor movements are present.

It is important that the patient is mobilized early after surgical treatment to avoid complications from lying in bed. The exercises consist of training stability of the torso, orthostatic training and moving exercises and they should be customized according to the level of the injury and after the function of the patient following surgery. (14) Much of the training used for other patients with spinal injuries can be used also for these patients. The difference being, that after mobilizing following a pathological fracture, difference in pain pattern and that the illness itself and ongoing treatment can affect the general condition of the patient and hinder mobilization.

Pain- relieving treatment like with TENS and acupuncture, can also be of help when the patient has pain from metastases of the skeleton. (14)

Other severe symptoms that can be treated by a physiotherapist

Fatigue

Everybody can relate to tiredness. Most of us have at some time felt totally exhausted and without energy and that can most often be cured with rest and a good night’s sleep. People with cancer can describe an unusual and extreme tiredness which does not disappear after resting or sleeping. They feel as tired when they wake up as when they go to bed. The tiredness is felt like a chronic feeling of unpleasantness, lack of energy, lack of concentration and forgetfulness. In health care the term fatigue is used for this experience, a word that can be found in the English and French language but has no equivalent in the Swedish language. When speaking with a patient the words tiredness or weakness is often used. (15)
Fatigue has been defined as “a subjective feeling of tiredness, powerlessness and lack of energy.” (16) This symptom occurs frequently and 80% of all cancer patients experience the symptom as troublesome. During chemotherapy treatment more than 99% of the patients state that they are bothered by fatigue. Fatigue has a very negative impact on the quality of life of these patients.

One of the latter definitions (2007) of cancer related fatigue has been set up by the National Comprehensive Cancer Network (NCCN). “Cancer-related fatigue is a distressing, persistent, subjective sense of tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning.” (17)

The cause of fatigue is not known. Different factors like the disease itself, consequences of the disease like anemia, infections, cachexia, anxiety, stress and depression can play a role in developing the symptom fatigue. (15)

Assessment:
Talking to the patient can give you an idea of the severity of the fatigue the patient is experiencing, how it affects daily life, if it changes during the day etc. A useful assessment tool is Borg-CR 10 scale.

Treatment:
Physical activity can lead to increased energy for other activities.
Advice - rest often - but for a short time each time. Advice the patient to plan activities so as to use the strength for what is important to him/her.
Walking can be a useful activity and it is important to ensure that the patient is well nourished and hydrated.

Both research and clinical evidence show that physical activity has the best effect in decreasing fatigue (18, 19, 20, 21, 22)

Most of these studies on fatigue and physical exercise have been carried our when the patient is receiving treatment or after treatment. Different types of physical exercises were included e.g. gymnastics, fitness exercises and mobility training. There are few studies with regard to patients where the disease is no longer curable, and also these studies show that symptoms of fatigue decrease with physical activity. (23)
**Physical weakness**

Decreased muscle strength and perseverance is common with patients who have an advanced chronic illness. The causes can be inactivity due to other symptoms like fatigue, pain and dyspnoea and aversion to eating which generate a lack of energy.

Patients in an advanced stage of cancer often show a visible loss of muscle mass because of increased protein destruction and a decrease of the protein synthesis in the skeleton muscles. Some medication like corticosteroids also give a loss of muscle mass, which is noticeable especially in the quadriceps muscles. (7)

To lose physical capacity is very stressful for most patients. Tiredness and worry make it difficult to take the initiative to take on activities and to move on their own. Many patients do not feel confident with their own body. How much are you allowed to do, is it acceptable to push yourself etc? The patient is afraid of putting too much burden on family and close friends when there is an increasing need of help as the body is failing.

An important role as a physiotherapist is to support the patient to carry out activity or exercises on his/her own. To do functional exercises, to be able to be independent in daily life, like for example be able to go to the toilet on ones own, is valuable for the patient. Inspire the patient by showing the resources the patient has. See the possibilities!

An improved physical status can give the patient a feeling of being in control and improves self respect. Increased self esteem can result in better social relations and reduced fear and anxiety. (24)

**Assessment:**

Is the disease causing bodily restrictions, if yes of what kind?
How does the patient handle the everyday activities, moving, walking upstairs, managing thresholds etc?
How much can the patient manage and what does the patient want to achieve by exercising?

**Treatment:**

Physical activity can be defined as all bodily movement produced by skeleton muscles and resulting in an energy use. When physical activity is planned, structured and recurrent it is called physical exercise and is aimed at improving or maintaining a special physical function. (18)
Physical activity reduces the risk of thromboses, the levels of stress decreases and it works as a prophylaxes for decubitus, improves breathing, keeps the stomach active etc. The exercises can be done individually or in a group. They can be functional exercises with specific activities, or more general movement exercises – or general health condition exercises.

The goal with physical exercises for cancer patients in a palliative stage is to gain positive effects on general health, strength of muscles, balance, psychological wellbeing, anxiety/worry, depression and quality of life. Focus should be on keeping movement and function.

Dosage of training is important and is diverse for different individuals. The background of people vary, some have never exercised before where some have had physical training as a lifestyle. A person who used to run several miles a week might not think that walking is exercise, even if the physical ability does not permit running. It is therefore important to encourage the patient to see “here and now” and not to compare with what the patient was able to before coming ill.

Access to a pool can be valuable. To exercise, movement, strength, balance and coordination in water is weight relieving and the patient can often perform movements he/she cannot do on land. Using floating devices movements can be carried out also lying in the water.

Many patients can use exercise machines. Choose some that are functionally well suited and start on a low level both with weights and the amount of repetition. It is important that the patient will not become exhausted. Strengthening exercises with barbells, weight cuffs or rubber bands are good alternatives if the patient is at home or no other equipment is available. Qi gong or yoga are other forms of exercises that prove useful and can also be executed sitting down. Access to passive cycling, tilting table and support for standing can ease mobilizing the patient.

Even bed bound patients can gain by physical exercise. To be helped to move against manual resistance, actively relieving or totally passive often gives a good feeling.

There is strong evidence of positive effects of physical exercises for cancer patients for physical function, muscle strengths, well being, anxiety, depression and in a wide sense quality of life. (22)
Pain

Pain is a common symptom with patients in an advanced stage of cancer disease and it forms the entire life situation for the patient. The pain is often caused by the cancer disease and the location of the tumor and the metastasis.

Radiation and chemo therapy treatment can cause both acute and a more continuing pain but can also relieve pain in a late palliative phase of the disease. With cancer diseases a general weakening of the body occurs including a reduced immune system resulting in the patient being more prone to thrombosis and herpes zoster which also can cause pain.

Many patients worry when they feel a new pain they have never felt before and their thoughts go immediately to the cancer disease. It is good to know that the pain is not necessarily always related to the cancer disease but these patients can also get a sore muscle or a head ache like anybody else. The pain can also be secondary, such as from metastasis in the skeleton which can cause tension of the muscles. Many elderly patients can have other diagnosis that can cause pain, like e.g. arthrosis. (13)

Pain caused by cancer disease can be acute or durable. It can be a nociceptive pain from the metastases of the skeleton, neurogenic pain caused by pressure of the nerves or visceral pain from tumor growth in inner organs. Pain caused by cancer disease can also be referred pain. It is common that cancer patients can have more than one kind of pain and when the disease is in the final stages the percentage of patients with pain increases. (13, 25)

As pain is a symptom that influences the patient’s quality of life it is important to work with a palliative holistic point of view. This means that the pain might not be just physical but can also have psychological, social and existential dimensions. In this situation other professionals likes social workers, psychologists, priests etc can add their competence to reduce the patients suffering by psychosocial and existential support (13).

Most cancer patients in late stages of their disease receive pharmacological treatment for pain. As a physiotherapist you can suggest other forms of treatment that, combined with medication, can increase pain relief. (5) Medication for secondary muscle pain does not work well and physiotherapeutic treatment can have a good effect in these cases. (13)
**Pain analysis**

Before choosing what kind of pain treatment to use a common judgment and examination needs to be performed where locality and range as well as character and intensity of the pain is analyzed.

What causes relief and what makes the pain worse?

Does the pain inhibit movement?

Has sensibility been affected?

How is every day affected?

What type of pain is it: nociceptive, neurogenic or visceral?

Is pain correlated to movement or is it painful when resting?

**Different methods of pain treatment**

**Physical activity /mobilizing**

**Assessment:**

It is important to observe the general condition of the patient.

What physical activities do not worsen the pain?

What motivation for activity has the patient?

Are there metastases in the skeleton with risk of fractures?

How does the patient manage to move?

**Treatment:**

Common exercises for patients with pain who are in a palliative phase of the disease are supported movement exercises, with a gliding mat, with a manual support or if possible in a pool. Exercises to practice movement are also common in order to find less painful and if possible pain-free ways to move. The goal is to make the patient unafraid to move and thereby avoid problems connected with immobility. An active treatment is often combined with other more passive alternatives in the pain treatment.

To increase e.g. strength, endurance, coordination and stability exercise can have positive effects with patients who have a long history of pain. There is strong evidence for physical exercise with different problems with pain like e.g. lumbago, where activities have to be individualized. The studies are not made specifically on cancer patients (26, 27).
**Massage and relaxing techniques**

Massage is defined as treatment of the body’s soft tissues carried out manually with the aim of getting a vascular, muscular as well as a nervous system response. (28) Massage is one of the oldest known forms of healing that goes back 5000 years in China and has many positive both physical and psychological effects. Touching in connection with massage sets the body’s own substances e.g. oxytocin and serotonin free. They have a calming effect and reduce pain.

Relaxing techniques are often given under the guidance of a physiotherapist or in the form of a taped program. The program informs the patient on how the relaxation can be carried out and the patients can handle this program by themselves. Both massage and treatment with relaxation can be given in order to reduce tensions of the muscles which have occurred due to pain. (29)

**Assessment:**

In what stage of the disease is the patient?
Has the patient pain when palpated?
Is the skin frail?
What can the patient psychologically accept?

**Treatment:**

Many patients in a late palliative phase of the disease have reduced muscle mass and frail skin because the protein destruction and corticosteroids. This makes a lighter massage more suitable for these patients. In many palliative care units a light touching massage, tactile massage or soft massage is used rather than manipulating the soft tissues.

Massage can be given during all phases of the disease. Massage gives relief during and immediately after treatment. (11)

Different relaxing techniques like progressive relaxation and autogenic exercise lying down or sitting as well as using a floating device in the water can help people relax.

Studies show that massage as pain relief can work for a short while for cancer patients. (28, 30, 31) There is not enough evidence to make conclusion about the effect of massage compared to other treatment alternatives. (26) There is also contradictory evidence that relaxation helps with enduring pain. There is also not sufficient knowledge about the effect with relaxation with neck- shoulder- pain, rheumatic arthritis, myalgia or head ache. (26)
**Heat and cold**

Treatment with heat increases the circulation locally where the heat is applied and it has a relaxing effect on the muscles. Cold can be used as pain relief in an acute injury and reduce the swelling that occurs and that can cause pain. (28)

**Assessment:**

Check if the patient has intact sensitivity and can judge if the temperature is appropriate.

**Treatment:**

Heat is often used to ease pain like a hot pack, or a moist towel put in a plastic bag in the micro which is easy to use and has a relaxing effect.

Cold is not applied as often but can be used when an acute injury occurs.

According to clinical experience the feeling of pain is reduced when the hot pack is applied and still warm.

**TENS - trans cutan electric nerv stimulation**

TENS activates the body’s own system to reduce pain. With high frequency stimulus impulses sent to the nervous system the pain reducing mechanisms blocks the pain through a so called gate-control. With low frequency stimulus endorphines are set free which ease the pain. TENS can be used with nociceptive and with neurogenic pain. (26, 29)

**Assessment:**

It is important that the patient can explain about the area of pain to decide if the intensity of the TENS- stimulation is correct. Check that the patient has sensibility. Contra indications are the same as with other patients that have pain.

**Treatment:**

It might be necessary to test the intensity several times before finding the correct placement of the electrodes in order for TENS to give the best pain relief. After instructions TENS can be used by the patient and that gives the patient the possibility to get better control of the pain. The electrodes can sit during the whole day and the patient can start the treatment by himself when the pain starts.
There is not enough evidence to suggest that TENS treatment has effect on chronic pain or cancer pain. But there are studies showing positive results of TENS-treatment resulting in pain relief. (26, 32, 33)

**Acupuncture**

Since 1984 the Swedish National Board of Health and Welfare has allowed acupuncture as treatment for pain. With traditional acupuncture special needles are applied intra muscular in specific acupuncture-points. Acupuncture brings a central inhibition of pain through setting free endorphines, serotonin and noradrenalin and also a segmental inhibition through setting free enkefalin which leads to less activity of the sympathetic nervous system and this reduces muscle tonus. Acupuncture also stimulates the setting free of other neuropeptides that cause increased circulation and has an anti inflammatory effect. (26, 29)

**Assessment:**

The patient should be cognitively clear and not be at the end of life. Contra indications are the same as for other patients with pain.

**Treatment:**

Acupuncture can be used as pain relief in combination with other pain relieving treatments. Usually acupuncture is given twice weekly but when a treatment series of several weeks is not feasible a daily treatment can be tried, in order to get a quicker effect.

There is strong evidence that acupuncture has a pain relieving effect with several different pain situations. (26) Acupuncture for cancer patients is useful to relieve symptoms. (34) Acupuncture can play a role in palliative care and reduce neuropathic and visceral pain. (35) Acupuncture can be used to give a short pain relief for patients with cancer pain in a palliative stage of the disease. (31)

**Edema – Lymphatic edema**

A common symptom that occur, for patients in a late palliative stage of the disease, is edemas in different parts of the body. They are caused by reduced activity, deep venous thrombosis or failure of the heart, liver and kidneys. Lack of albumin often in a late stage of the disease can cause general edema, but is more often concentrated in the legs.

Many patients have several causes for the edema. It can be the result of a tumor or the patient’s lack of albumin leading to an edema. It can cause a general edema from the lower parts of the
extremities up over the torso to the arm pits. Patients can have the feeling that the edema causes heaviness and a tension as well as a feeling of weightiness. Many become disabled as a result of the edemas.

Lymphatic edemas are caused by the lack of transport capacity in the lymphatic system. It can occur after in a growing tumor, after surgery or radiation, after infection or be congenital. Lymphatic edemas most frequently occur in arms and legs but can also occur in the torso, head and neck area and in genitals which very often is experienced as very intricate.

For patients in a late palliative stage of disease medication with corticosteroids is quite common. Corticosteroids make the skin become very frail which increases the risk of skin infections like erysipelas that can be treated with antibiotics. Wounds or lymphatic fistulas increase the risk for leakage of liquid through the skin, so called lymphatic leakage. (7, 36, 37, 38) Good skin care like using a softening skin lotion can prevent wounds and reduce the risk of skin infections.

Assessment:
Differential diagnosis is made together with a physician to diagnose or exclude thrombosis and/or suspected erysipelas.
How did the swelling start and where is it situated and does it change during the day?
How does the skin look?

If some other parts of the body rather than feet and legs are swollen and if you feel uncertain as to how the patient is best treated - consult a lymphatic therapist.

Treatment:
The most common treatment for at patient in a late stage of palliative disease with swollen legs is to try out compression stockings in compression class I, so called anti thrombosis stockings. If the skin is fragile the extremity should be bandaged. The expected effect of the treatment is to reduce the volume of the edema, improve the status of the skin and to stop the leakage of the lymphatic liquid and improve function. (7, 36) Make sure that the edema does not move from the leg to the abdomen or to the genitals. When the patient is in a late palliative stage of the disease, make an assessment of the effect of improved function and reduced unpleasantness as well as that the treatment does not hinder the patients daily activities.

Combined Decongestive Therapy – CDT is an established treatment method used in Sweden and internationally and is carried out by lymphatic therapists. The therapy consists of
compression, manual lymphatic drainage, advice and regime, skin care and exercises. The most important component is compression, either through stockings or bandaging. The patient should take active part in the treatment as much as possible.

Manual lymphatic drainage can give relief, reduced edema and also relaxation.

The clinical experience of compression is very good. Evidence for the effect of manual lymphatic drainage as a treatment added to compression for patients with an arm edema after breast cancer is limited. (39, 40) There are few studies made with patients having an edema or a lymphatic edema in late palliative stages of the disease.

**Dyspnoea**

Dyspnoea is a common symptom for patients in the late stages of a cancer disease. 70% of patients with lung cancer report having dyspnoea. Common causes for dyspnoea are pleura liquid, ascites or enlarged liver. Many patients with lung cancer also have other diseases like COPD and fibrosis of the lung caused by radiation which also can cause dyspnoea.

The feeling of gasping for air and the experience that it is tiring to breathe are used as criteria for dyspnoea. It is often associated with physical efforts or psychic strain and creates anxiety.

Severe dyspnoea when speaking is frustrating and can make socializing with other people almost impossible. The experience of dyspnoea is subjective and can not be measured objectively, but the intensity can be estimated with VAS or Borg-RPE scale. (7)

**Assessment:**

Read the anamnesis from the patient’s records.

Look at the breathing pattern; does the patient use accessory breathing muscles?

Does the dyspnoea stop the patient from carrying out functional activities?

Can the patient cough when he/she has problems with phlegm?
Treatment:

Give instructions for useful sitting positions and movements so that they are made with as little effort as possible. Aids such as a walker, other gait aids or wheelchair are facilitating. Give instructions in resistance, blow through closed lip breathing. Another option is that the patient can blow in a hose - 1cm in diameter - in a bottle filled with water that makes light resistance.

A so called BA-tube and breathing trainer can also be of help.

Breathing exercises are very important, ordinary deep breathing where the patient is encouraged to, if possible, inhale through the nose and exhale through the mouth. Breathing is exercised through making the patient observant of the synchronized movements of the abdomen when breathing by e.g. putting a hand on the stomach. This can be combined with closed lip breathing. If the patient has phlegm use coughing support. Give instructions about the huffing technique if the patient has difficulty coughing.

The physiotherapist can instruct the inhalation technique when using nebulizing equipment when the patient needs to inhale medication or natrium clorid solution. To stress the relationship between muscle tension and breathing, exercises for the shoulder and chest are carried out. Massage of the shoulders and neck can reduce anxiety.

For patients in a later palliative phase of the disease, where breathing exercises can be too tiring, instructions on resting positions can be more relevant. Different resting positions give a relaxation of the muscles that can facilitate breathing and lessen dyspnoea and anxiety. It is important to give information also to the family to create calmness, comfort and well-being for the patient.

Most of the studies have been carried out on COPD-patients, some studies were carried out on patients with an advanced cancer disease. There is reasonably strong evidence for breathing exercises and using walking aids to minimize the efforts (41).

Nausea

With an advanced cancer disease 40 – 70 % of the patients are troubled by nausea and vomiting. (5) These symptoms can be triggered by different causes. The cancer disease can cause ileus/subileus and so can metastases in the liver and brain which can cause nausea and vomiting. Treatment with chemotherapy, radiation and other medication and former abdominal surgery can cause nausea and vomiting. Nausea can be triggered by moving as well as by symptoms like anxiety, constipation and pain. (25)
Assessment.
Find the cause for the nausea before starting any treatment. Physiotherapeutic treatment options for nausea are most effective with nausea caused by treatment. Nausea caused by the disease is often a mechanical hindrance or stop where it is doubtful if physiotherapy treatment has any effect. Nausea can be evaluated with VAS.

Treatment
Most treatment aims at stimulating the acupuncture point PC6 on the inside of the under arm, two thumbs (the patient’s thumb) away from the wrist pleat. Stimulation is done bilaterally if possible and can be done daily. Treatment options are acupuncture, electric-acupuncture, acupressure, TENS and motion sickness bracelet. When nausea is caused by chemotherapy, it is good if possible to start treatment 1-2 days before the chemotherapy treatment starts. Light massage has been shown to reduce chemotherapy triggered nausea in the short-term. (42)

Acupuncture increases the antiemetic effect of medication post surgery and with chemotherapy triggered nausea and vomiting. (31, 35, 43) There is uncertainty about the effect of treating with acupuncture for nausea for patients in a late palliative stage of their disease. (44)

Constipation
The pain relieving medication which patients receive in late stage of a palliative disease is often morphine (opioids) which affects the peristaltic so that the bowel movements slow down. That is the reason many cancer patients in palliative care have problems with constipation and opioid treatment is therefore always combined with laxatives. Other medication like diuretica and anti depressives can also cause constipation.

Constipation gives the patient an impaired quality of life, life is affected physically, psychologically, socially and existentially. Feelings of panic, helplessness, of death anxiety and shame have been described and the painful physical symptoms can over shadow everything in life. (45)

Assessment:
Assessment is done by talking to the patient and through information from the nurse or the physician.
**Treatment:**

Physiotherapeutic treatment of constipation is indirect through physical activity. It is important that the patient moves as much as possible in relation to his/her the condition. Different forms of exercises complement other medical treatment methods.

There are different massage methods described where the aim is to start the movements of the bowels and to reduce the amount of abdominal distention.

Clinical experience shows that physical exercise can improve the condition when the patient is constipated. (46)

There is not enough scientific evidence to use massage as treatment for constipation. (47, 48)

**Other physiotherapeutic activities**

**Orthopedic aids and technical aids**

Orthopedic aids like back girdles, neck collars and other kind of orthoses can be helpful to stabilize a joint or some vertebrae. Most of the patients needing these aids have often had metastases of the skeleton and / or pathological fractures.

Technical aids like walking aids and wheel chairs are needed by more or less all patients in a palliative stage during some time during their illness trajectory.

**Instruction and supervision**

The physiotherapist can instruct staff and family to help the patient when moving so that it can take place in a safe and careful way for all included. The physiotherapist can also show how to help to move the patient’s joints when the patient is unable to and to find positions of rest.

When using TENS or massage, the family member can be instructed how to do it and help treat the patient. All this is of course made in agreement with the patient and the family. It is important to be sensitive to the patient’s and the family’s wishes and needs of involvement and to respect the ones who do not wish to or cannot be involved.
**Patient cases for discussion and reflection**

1.

A 58-year old married man with 3 grown up children lives in a modern apartment with his wife and has his own company in sales business. He was diagnosed with prostate cancer 2 years ago and had curative treatment. After the treatment he worked until 4 months ago when his back pain started. Examinations showed metastases in the skeleton, in the right femur and in the TH3 and TH10 of the thoracic spine as well as L2-L3 of the lower back.

A deterioration of his status has occurred in the last month as the metastasis on L2-L3 has led to a compression of the medulla. The patient has been laminected and is stabilized on this level. He has received radiation for his metastasis on the vertebrae and also on the left hip as pain relief.

The strength in his legs is on level 2-3 on a 0-5 scale, he has bilateral leg edemas and the sensibility is reduced. The patient has difficulties when stretching because of his pain and he quickly becomes tired and gets dyspnoea with effort. He is very positive about exercising and has tried to stand up with a walking table but the legs do not carry him. The patient wishes to be able to walk again as he is going home and is needed at work.

*Which goals can be realistic? Any restrictions? What are the appropriate exercises for mobility and strengths? What treatment should be given for the edemas? What if any physiotherapeutic pain treatment? Breathing exercises? Aids?*

2.

A 50-year old man with 3 teenage children. Formerly healthy and sporty. Diagnosed with a brain tumor, glioblastom, one year ago. Has been operated on and twice treated with chemotherapy. Temporarily improved but his status is deteriorating with weakness on his left side and loss of sight. He needs supervision when walking. He is also slightly cognitively impaired which makes him not always realize his limitations and he forgets that his balance is reduced.

*What can you do as a physiotherapist to facilitate the family? Explain the physiotherapeutic goal. In need of aids? What exercises could be useful?*
3.
A 64-year old woman living alone with a newly diagnosed lung cancer that has spread to the skeleton. She lives in an older apartment with a small elevator. She had a spontaneous fracture of the right femur and has been operated on and received a hip replacement. Free mobilization is permitted, but she should not be sitting with less than 90 degrees in her hips and not cross her legs. She has anxiety and is very afraid when mobilized to a standing position. She does not trust her leg and has pain in the operated area when moving.

Give an example of the goal for the physiotherapeutic treatment. In what phase of the crisis is the patient? What other professions could be useful to consult in her rehabilitation? How can the physiotherapist support the patient? Suggest initial movement exercises. Which aids does the patient need?

4.
A 70-year old man living alone. He was diagnosed with ALS a few years ago and has now constant assistants. He has a ventilator 24 hours and a cough-assist to get rid of the phlegm. He has progressively had more difficulties in moving. Previously he was able to sit in a wheel chair that he could handle on his own. Now he has an electric wheel chair that he still can manage in his house if he gets help to put his hand on the joy stick. He is now troubled by weakness of the muscles and pain in the neck-shoulder area and that makes it harder for him to hold his head. His lower legs have begun to swell.

Suggest the physiotherapeutic goal for the patient. Is there a form of exercises that the patient can handle actively? Is there a need for passive treatment? Does the patient need orthopedic aids? Suggest how his leg edemas should be treated.

5.
A 25-year old woman living with her boyfriend. She is in close contact with her parents and 2 siblings. She has breast cancer in her left breast that has spread to the lymphatic nodes two years ago. Initially she was treated with chemotherapy and afterwards had an operation and was then treated with radiation. For the past two months she has metastases in the liver and the lung. She has a lymph edema in her left arm and has had a compression stocking which is not
functioning. She also has pain in her neck and in the left shoulder. She is used to exercising and feels that she has a hard time exercising as usual as her body does not obey her and she becomes breathless very quickly. She has a wish to exercise but needs to get her exercise program adapted to her new physical condition.

Suggest the physiotherapeutic goal for the patient. What kind of exercises could be useful? How can she be helped with her lymphedema? What could be the reason for her pain? Is there a need for more investigation of her pain? What kind of treatment for her pain would be useful to try?

Finally

Physiotherapeutic palliative care is by necessity focused on the body. For a person in the most problematic time of life, just before leaving life, it is painfully clear how important the body is. Movement is a symbol of life and maybe it is the most important time to move when one is no longer able to, to feel that one is still alive and get confirmation that one still belongs to life.

Today it is essential to have a rehabilitative approach as people live longer, but often with functions reduced due to treatment. Physiotherapists have - with their specific competence - a task to prevent, examine and treat functional barriers that limit or threaten to limit the human movement. By facilitating the patient to keep or improve functions or through technical aids the independence and the quality of life of the patient can improve, in all stages of life.

Please note that the physiotherapist’s symptom relief and activating treatments have very few side effects!

The exercises and physical activities that the physiotherapist offers resemble life when the patient was still healthy. This gives the patients some breathing-space, pausing from thoughts of illness and death - an important rest for the patient and a possibility to recuperate.

Physiotherapists must always strive to base treatments on best available knowledge. The existing evidence for different physiotherapeutic treatment methods are in some areas not sufficient and in palliative care few studies have been carried out. This does not mean that the treatment is useless but that there is a need for more research in this area.
Through increased knowledge about physiotherapy treatment methods for patients in the last stages of life we hope that this group of patients will receive a better quality of life.

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