

Physical and occupational therapies in palliative care

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INTRODUCTION

With the current overall survival rate at 50%, cancer is now considered a chronic disease, joining the ranks of other major chronic conditions (cardiovascular disease, lung disease, and dementia) that account for end of life.¹ Treatment of any of these life-threatening diseases, especially in those who are elderly, results in a variety of medical problems, complex functional changes, and a significantly compromised quality of life.²⁻⁴ People with cancer and other serious illnesses require comprehensive care designed to relieve symptoms of pain, fatigue, and weakness during all phases of their disease including pretreatment, treatment, posttreatment, recurrence, and end-of-life phases.⁵ Providing that level of comprehensive care requires a team of health professionals who can address both curative care and palliative care issues regardless of where the patient is on the life-death continuum. However, the World Health Organization (WHO) has recognized that it is unrealistic to expect that emerging palliative care needs can be met simply by training a workforce of specialists in palliative care. WHO suggests that expanding the knowledge and skills of health professionals in general is the answer to addressing the increase in health-care needs as individuals begin to live longer.⁶ The key to increasing the numbers of health professionals who can improve patient function and quality of life among seriously ill patients and their families is to enhance the awareness and skills of physical therapists and occupational therapists so that they will feel confident in working with palliative patients and their families.

Approaches to cancer patient rehabilitation that take both psychosocial aspects and physical aspects into consideration are important, based on the reported need of “adequately understanding the strong connections between the patients’ physical, psychological, and social aspects.”⁷ Thus, the involvement of representatives of a variety of occupations, including psychologists, clinical psychologists, and nurses, and not just rehabilitation specialists such as physical therapists or occupational therapists, is important for the rehabilitation of cancer patients; thus, multidisciplinary team care is required. However, not many reports on the rehabilitation of cancer

patients have appeared since comprehensive research reports on the need for rehabilitation were first published by Lehmann et al.⁸ in 1978 and by Harvey et al.⁹ in 1982. One reason for this lack of research is that as rehabilitation was originally performed mainly for the purpose of improving and raising the level of activities of daily living (ADLs), there has been little demand from either health-care providers or patients for proactive intervention in cancer care with regard to rehabilitation, which has had the strong image of being intended to improve ADL and return patients to their former lives. In recent years, however, interest has turned to the association between cancer rehabilitation and the increasing numbers of patients who survive for long periods while enduring symptoms caused by cancer or the adverse effects associated with treatment or the association with advances in palliative care.

While physical therapy and occupational therapy are traditionally viewed as rehabilitation interventions, providing rehabilitation services for terminally ill patients is not a new concept. Dietz¹⁰ has classified cancer rehabilitation according to cancer patients’ physical and individual needs into four categories: preventive, restorative, supportive, and palliative. Based on these categories, the effectiveness of rehabilitation has been reported for each stage of cancer treatment, from physical rehabilitation during the acute stage of treatment^{11,12,13,14} to the rehabilitation of physical aspects and psychological aspects during the terminal stage,¹⁵⁻¹⁷ but it remains difficult to claim that cancer rehabilitation is generally acknowledged to be adequate. In view of these situations, Dietz¹⁸ has pointed out the need to focus on a concept of care that asks, “What is the best support that can be provided to enable cancer patients to readapt to society?” DeLisa¹⁹ has also stated that “now that cancer patients’ survival rate has increased, attention should be turned to maintaining cancer patients’ quality of life and prolonging it.” In other words, a shift to an approach that aims to maintain the quality of life of patients at a high level and not just improve their function and prognosis has become necessary.

The benefits of physiotherapy in palliative care were recognized in the United Kingdom in 1978. Shank²⁰ described the physiotherapist’s role as the *relief of discomfort and pain* through the use of massage, exercise, supportive positioning, splinting, and chest physiotherapy and the

Box 102.1 Role of physical/occupational therapy in palliative care

- Help patient determine which activities and roles they can realistically perform.
- Enable the patient to take an active part in establishing goals and treatment priorities.
- Apply physical/occupational therapy interventions to minimize symptoms and optimize functional abilities.
- Assist the patient to find meaning with their available range of activity and occupation considering the interplay between physical, psychological, social, and vocational domains of function.
- Instruct patient regarding methods to maximize function within limits of energy, safety, and capabilities.
- Enhance quality of life at the end of life for the patient and their family.

maintenance/improvement in function through the use of assistive devices, exercise, and retraining. She concluded that the retention of an element of independence could provide the patient with valuable hope and reduced anxiety. About the same time, occupational therapists advocated that good end-of-life care should include not only the management of symptoms but also assistance to make the best of every day. In 1983, Tigges and Sherman²¹ described the role of occupational therapists in fostering hospice patients' independence in occupational roles of self-care, work, and leisure as important interventions in coping with feelings of isolation and the loss of independence (Box 102.1).

WHEN TO MAKE REFERRALS

In developed nations, people are living longer and the types of diseases that they are dying from include chronic diseases often associated with musculoskeletal disorders and disabilities. Heart disease, stroke, pulmonary failure, and cancer are recognized as the main causes of death, but comorbid conditions such as arthritis, dementia, and osteoporosis are also contributing to increased levels of disability and the need for additional care.²² In a study published in the *Journal of the American Medical Association*, clinicians examined the patterns of functional decline at end of life for four types of illness trajectories (cancer death, organ failure death, sudden death, and frailty) and concluded that "end of life care must also serve those who become increasingly frail even without a life-threatening illness."²³ Additionally, research from WHO indicates that palliative care interventions such as good pain relief, communication, information, and coordinated care from skilled professionals are effective for reducing symptoms and suffering and that these experiences do not differ widely according to disease or across countries.²² The decision regarding when to begin physical and

occupational therapies for palliative care patients is often based on the need to manage symptoms early during the course of the disease or to improve the quality of life of the patient.

Early referrals for symptom management

The use of palliative care interventions is applicable early during the course of an illness (and not just at the end-of-life stage) to manage distressing clinical complications. Physicians may not consider the benefit of physical and occupational therapies early during the course of cancer or cardiovascular or respiratory diseases; however, preventive interventions offered by these rehabilitation specialists may prevent pain and functional loss during the end-of-life phase of these diseases. Gerber noted that referrals to rehabilitation professionals for cancer patients usually target either specific impairments at an anatomical level (i.e., a loss of range of motion [ROM] or lymphedema) or problems with mobility. However, she recommends earlier referrals to prevent predictable problems associated with medical treatment, such as skin care and exercise to manage connective tissue side effects from radiation.⁵

Recent studies have demonstrated that the benefits of exercise include improvement in mood,^{24***} physical capacity,^{25***} fatigue,^{26***} and quality of life.^{27***} Exercise can prevent the loss of strength and functional abilities often associated with a lack of activity or disuse in the cancer population.^{28***} Even with bone marrow transplant populations, Demeo^{29**} has shown that exercises can be done safely immediately following high-dose chemotherapy and can effectively reduce fatigue, maintain physical performance, and improve hemoglobin levels.

Improvement of quality of life

Quality of life has different meanings for different persons. For measurements of quality of life to be considered valid, the definition of quality of life must be determined based on what the individual identifies it to be at a given point in time.³⁰ Calman³¹ proposed a model for assessing quality of life in which quality of life is defined as the difference (at a particular period in time) between the hopes and expectations of the individual and their present experience. The gap between hopes and realities may be narrowed by improving patients' function through treatment or by reducing their expectations through a better understanding of the limitations imposed by their disease. Using this model, improving quality of life for palliative care patients is a dynamic process that must continually address the ongoing changes in the gap between hope and reality as their disease progresses. Physical therapists and occupational therapists, by the nature of their therapeutic and educational interventions, can and often do assist seriously ill patients to manage this gap between hope and reality.

Nolen and Mock³² noted that, in addition to the importance of having control over traditional ADL (bathing, dressing, and eating), having functional control over health-care decision making and fulfillment or role expectations are equally

Box 102.2 When physical or occupational therapy is appropriate for palliative patients

- Any patient with a serious illness can benefit from therapy services.
- Physical/occupational therapy can provide specialized treatment of pain, discomfort, and functional loss at any stage of illness.
- Referral is encouraged early in the patient's care to prevent predictable morbidities but can be received at any time, including during and after curative treatment.
- Therapy services can be provided in hospitals, nursing homes, community settings, the patient's home, and the hospice/palliative care unit.

important to patients at the end of life. Occupational therapists can tailor treatments and goals to allow patients to continue to carry out meaningful activities and to fulfill self-identified important life roles. Yoshioka³³ demonstrated the importance of patient control over health-care decisions in his study of 301 cancer patients who received rehabilitation therapy during their last 6 months of life. Although the mobility and self-care scores improved with therapy in all the participants, the patients and families who received the greatest benefit were those who more actively participated in their rehabilitation and helped to direct their care.

The improvement in quality of life through physical and occupational therapy interventions has been shown to be beneficial at every stage, even during the last days of life (Box 102.2).³⁴ In a study of 56 cancer patients in Switzerland, the benefits of physical therapy were noted right up to the last 24 hours before death;³⁵ 79% of the patients received beneficial respiratory management techniques during the 24 hours preceding their death, and 55% received beneficial interventions aimed at improving self-care during the 8 days preceding their death.

GUIDE FOR PHYSICAL/OCCUPATIONAL THERAPY IN PALLIATIVE CARE

Therapeutic goals

Goals should be realistic and should take into consideration numerous interrelated factors such as age, stage/type of disease, social/economic factors, and cognitive abilities. The process of setting appropriate goals is as important as the goals themselves. Although all patients should collaborate in the development of their rehabilitation goals, such collaboration is especially helpful to patients in a palliative care setting, as the process provides a therapeutic outcome of allowing the patient continued control in directing his or her care. Therapists in palliative care settings can encourage patients

to explore what is truly important to them at that point in their life. Collaborative goal setting can also provide an ideal opportunity to assist patients in reframing unrealistic goals in a manner that will match their current medical condition, if necessary.

Therapists' specialized skills

Physical and occupational therapists involved in the care of patients with progressive, debilitating illness or age-associated decline must demonstrate not only well-developed clinical skills but also the ability to communicate effectively, facilitate team interactions, and innovate extemporaneously. They must be sensitive to the emotional needs of the patient and family, as well as the needs of their fellow team members. In more ways than in any other rehabilitation treatment situation, the wants and needs of this patient population should drive the treatment plan. The palliative care therapist must be able to establish a treatment plan focused on comfort and quality of life, rather than on the recovery of normal function.

In the health-care culture, where there is often a general discomfort surrounding the topic of death, physical and occupational therapists traditionally focus on rehabilitation for living. However, in a palliative care setting, therapists must be able to manage their own fears and feelings about serious illness and death to provide effective support to the patients and their families who are facing these issues.³⁶ Trump³⁷ advises that to be effective in a palliative care setting, therapists may need to address and sometimes share in patients' and families' intense emotions. Furthermore, when death does occur, the therapist must have appropriate methods for bringing about professional and personal closure to prevent emotional burnout. Foles et al.³⁸ outline a series of professional and personal activities that promote emotional well-being for the therapist, including the attending of a wake, funeral, or memorial service that allows the therapist to say goodbye to the patient and family. Professional reflection on the outcomes of the therapy provided and reliance on one's own personal/spiritual beliefs and values are essential skills for therapists working in palliative care (Box 102.3).

Box 102.3 Special skills required for therapists working in palliative care

- Effective communication skills: Active listening, empathy, and intuition
- Problem-solving skills and creative approaches to individual needs
- Ability to form compassionate bonds with emotional detachment
- Ability to accept death as a reality but never take away hope

Assessment of functions

An objective assessment of function, which is routinely performed for all patients, allows the implementation of rehabilitation measures to slow, prevent, or remediate performance problems. Physicians and nurses typically evaluate function in patients with cancer using the Karnovsky, Eastern Cooperative Oncology Group (ECOG), or similar rating scales. These scales are not always true indicators of a person's actual physical abilities, as the ratings are usually based on cursory observations of the patient in an artificial environment (a clinic visit) in which they are "stimulated... by the environment, anxiety and expectations."³⁹ In a small study of patients with non-small cell lung cancer at the Jewish General Hospital in Montreal, Dalzell et al. compared the ECOG performance status (PS) ratings with a global functional score composed of three objective measures of performance. They found that "PS evaluation persistently underestimated the degree of functional disability, as measured by the objective measures."⁴⁰ Cashy and Cella⁴¹ compared the results of PS assessments for lung cancer patients performed by the physician versus the patient's self-assessment of their function and found that physicians, in general, rated the patients as performing better than the patients rated themselves.

A better indicator of the patient's actual functional abilities is objective tests of observed performance, in which the time or distance is measured. Functional performance tests, such as a 6 min walk, 50 ft fastest speed, and timed sit to stand, have been compared among groups (i.e., cancer, HIV, AIDS, and lower back pain). Although all groups showed an overall decreased performance from normal, the cancer patient group was the lowest performing group.⁴² Lee et al.⁴³ evaluated the self-reported fatigue measures and objective functional performances of individuals with lymphoma and recommended that physical performance measures be used in addition to self-reported measures when evaluating the outcomes of rehabilitation.

Physical therapy in actual practice

Giving priority to patients' wishes has become the basis for physical therapy interventions in palliative care, but their content ranges widely, from approaches intended to provide patients with a sense of achievement with regard to feelings of loss of physical strength on bicycle ergometers to supportive interventions by room visits (Box 102.4).⁴⁴

1. ROM exercises

The ROM exercises used in palliative care prioritize ROMs required for the performance of ADL, rather than the expansion of ROMs. Basically, ROM exercises are performed 5 to 10 times so as to understand the patient's normal ROMs (which will differ according to the joint) and not to induce pain. Patients are asked to cooperate with each movement, and care is taken to increase kinesthesia by having the movements accompany voluntary movements produced by muscle contraction. Because of

Box 102.4 Physical therapy interventions in palliative care

- Functional mobility training
- Therapeutic exercises
- Dyspnea management
- Positioning for skin care, comfort, and function
- Lymphedema control
- Orthotics
- Therapeutic modalities (heat, cold, massage, electrical)
- Caregiver instruction and training

the risk of inducing pathological fractures of long tubular bones when passive ROM exercises impose an external twisting force, guidance is provided so as not to produce any internal rotation or external rotation.

2. Muscle strength maintenance exercises

Muscle fatigue develops very rapidly in patients with disuse syndromes, and for all practical purposes, sometimes patients cannot even perform five repetitions. The resistance or active assistance must be adjusted, while flexion and extension exercises of the lower limbs are being performed so that the patients may experience a sense of achievement. Patients are asked to perform straight leg raises (SLRs, raising the lower limb with the knee in extension) as a means of evaluating the muscle strength of the lower limbs. If a patient can perform SLR without pain or without the action becoming unstable, then there is a strong possibility that the patient will be able to walk.

3. Approach to antigravity muscle groups

Muscle groups that act in opposition to the force of gravity are called antigravity muscle groups, and the term antigravity muscle groups mainly refers to muscle groups of the trunk, the quadriceps femoris muscle, and the triceps surae muscle. Based on the results of research conducted on elderly persons during long-term bed rest and, in recent years, on the weightlessness of astronauts, muscle atrophy is said to progress considerably in the absence of the stimulation of these muscle groups. Thus, training these muscle groups is important, and abdominal muscle exercises, patella setting as quadriceps femoris training, and plantar flexion exercises at the ankle joint, which can be performed even in the supine position, are recommended.

4. Support for getting out of bed

After learning the wishes of patients who tend to stay in bed because of their easy fatigability or lassitude, exercises from the standpoint of providing motivation to get out of bed are also conducted in the rehabilitation room. Even if there is only a brief time for conducting the exercises in the rehabilitation room, patients must be involved in getting out of their bed because this activity is associated with a change in their environment and the accompanying

transfer or sitting. The distance traveled during walking practice should be decided according to how tired the patient feels. Information sharing with the hospital unit should be established, and the time the patient spends out of bed and the amount of daily activity in the hospital unit should be gradually increased. When patients have been spending the whole day in bed, on the other hand, muscle atrophy has often already progressed, their nutritional and respiratory status is likely to poor, and they may tend to feel drowsy. Because of adverse effects such as nausea, pain, or fatigability, each rehabilitation session can often be performed only for a short time. In such situations, passive ROM exercises and active assistive exercises should be performed; in parallel, the bed should be progressively raised until the patient is eventually able to sit on the edge of the bed and to stand up. If the patient becomes able to maintain a sitting position, an attempt may be made to transfer the patient to a reclining wheelchair with assistance, and going for walks around the hospital also becomes possible. Performing physical therapy for patients with generalized wasting is aimed at the recovery of the functions of parts that can be improved and at improving the ADL; at the same time, an understanding of the risks involved is also necessary. When muscle atrophy has progressed, it is important to be careful that physical therapy does not result in lower limb fractures, which tend to occur because of muscle atrophy that has progressed and the absence of weight-bearing activities, or result in a lingering feeling of fatigue, orthostatic hypotension, resistance to exercise, and loss of self-confidence.

5. *General conditioning exercises*

If patients are capable of walking in the hospital unit, they are instructed in leg stretching exercises that can be performed in a standing position. The leg stretching exercises do not involve particularly difficult movements and consist of "Achilles tendon stretching," "adductor muscle stretching," and "ankle flexibility exercises" while holding onto parallel bars or a hand rail. When the patient is attached to numerous tubes, such as intravenous tubes and monitors, a 4-movement squat-stand exercise that can be done on the spot is performed. In movement 1 of the 4-movement squat-stand exercise, patients squat by slowly flexing their knees from a standing position; in movement 2, patients extend their knees and return to a standing position; in movement 3, patients lift their heels and stand on tiptoe; and in movement 4, patients lower their heels and return to a standing position. This exercise is performed from 5 to 10 times in a rhythmic manner. Because the load increases with the depth of the squat and the number of repetitions can be raised or lowered, the load can be adjusted to the patient's physical strength. This exercise is also very effective with regard to the antigravity muscle groups mentioned earlier.

6. *Use of simple training devices*

When the lower limb muscles are weak (manual muscle test [MMT], 2-3) and active exercises are unsuitable, devices that facilitate sliding and that are usually used for

transfer activities, such as slide boards and transfer slides, can be used. These activities make active exercises possible by reducing the frictional drag caused by gravity. Doing so is linked to the successful experience of being able to move by oneself, and it also provides motivation to continue exercises as so to maintain muscle strength. Using a walker with a load brake to support getting out of bed is also effective for patients with lower limb paresis as a result of spinal metastasis or muscle weakness in their lower limbs because of disuse syndrome. Walkers are used to fulfill the hope that patients in palliative care units express when they say "I want to walk to the toilet," and they are also used with the aim of lessening the burden on nurses involved in providing assistance.

Occupational therapy in actual practice

For patients and families facing problems related to life-threatening illnesses, occupational therapy sets the desired life or work activities as the goal/method, providing spiritual and psychological support as well as support for physical functions. In palliative care, it is important to determine the needs, hopes, and demands of patients and, taking energy allocation into account, to prioritize the approaches. Although this strategy is appropriate when the patient is able to specify his or her needs, hopes, and demands specifically, there may also be many times when it is difficult to confirm their needs because of the physical condition or mental state of the patients themselves. Moreover, there are also times when the patients and their families have no information regarding the possibility of conducting occupational therapy.^{45,46} Thus, in addition to the needs that have been elicited, latent needs that are expected to be more important to the patient or family are often hidden. To uncover such latent needs, it is important to also build trusting relationships, to confirm the social background and work history of the patient, and to provide the required information so that occupational therapists may provide support (Box 102.5).

Box 102.5 Occupational therapy interventions in palliative care

- Engagement in meaningful activities that reflect valued roles
- ADL training/adapted techniques
- Energy conservation techniques/fatigue management
- Assessment/training in use of assistive devices and modification of environment
- Group activities (emotional and social benefits)
- Orthotics
- Positioning for skin care, comfort, and function
- Caregiver instruction and training

1. *Reducing physical suffering*

- a. *Alleviating lassitude as a result of immobility*
When impaired circulation as a result of immobility causes suffering, such as fatigue or stiffness, it is sometimes possible to alleviate fatigue, stiffness, or pain temporarily by massage, stretching, or ROM exercise, promoting circulation in the muscles around the scapula. Moreover, when respiratory discomfort develops, pain and stiffness often occur because patients must spend more time sitting, and their antigravity muscles, such as the cervical-upper spinal erector spinae muscles, become constantly hypertonic. Heat may be used (with contraindications, such as avoiding the application of heat directly over tumors, kept in mind), and support to promote blood circulation can be performed in an attempt to relax the muscles.
- b. *Protecting upper limbs that are difficult to move*
When an upper limb is heavy and difficult to move freely because of brachial plexus paralysis or some other form of paralysis of the upper limb or because of lymphedema or some other type of edema of the upper limb, an attempt should be made to maintain the upper limb in the correct position through the use of an arm sling so as to protect it from hazards, such as wound during housework, and to prevent secondary suffering.
- c. *Positioning in a comfortable posture*
Sometimes pain occurs as a result of a tumor metastasizing to the axillary lymph nodes or lymph nodes around the collarbone, with subsequent growth compressing the nerves, or because the tumor has invaded a nerve. Although drug therapy is the mainstay of pain treatment, since the degree of pain likely varies with the position of the shoulder joint or the scapula, methods such as appropriate positioning so that the shoulder joint is unlikely to be subjected to excessive traction should be considered.
- d. *Alleviation of suffering and restricted movements as a result of edema during the terminal period*
In patients in the terminal phase of their illness, venous and lymphatic displacement, hypoproteinemia, or paralytic edema tends to develop as a result of advanced cancer. It is also often difficult to improve the edema itself, and because the body movements are limited by the edema and ROMs are limited, these limitations often become causes of patient suffering. It is important to minimize movement limitations by preventing fibrosis around joints and performing ROM exercises to maintain the ROM of major joints.
- e. *Preventing contractures*
ROM exercises and positioning to ensure the ROM mainly of the large joints, including the shoulder joint and the hip joint, are important so that contractures do not impede medical care and nursing care.

2. *Maintenance and improvement of ADL and instrumental activities of daily living (IADLs)*

Even when it is impossible to prevent declines in body functions, sometimes a patient's independence level can

be increased by making adjustments to ADL movement methods, making the most of their remaining functions, or introducing long-term care equipment and self-help devices. Movements that the patients can control themselves can be devised. It is also important to devise ways that require minimal amounts of energy and to make adjustments with regard to energy allocation, such as saving energy for other things that the patient wants to do. Some examples are listed in the following.

- a. *Modifying the ADL movements of patients in a generalized wasting state*
The overall physical strength of many patients with advanced cancer is depleted, and their ability to continue activities declines as a result of the impact of fatigue or diminished appetite, arising from the deterioration of their respiratory status, anorexia-cachexia syndrome, etc. It has been reported that the comparative "capability ADL" of patients who exhibit these symptoms but do not have motor paralysis or osteoarticular diseases is maintained until about 2 weeks before death, and that the "capability ADL" suddenly becomes difficult around 5 days before death. Movement methods that minimize energy (shortening movement lines, transfer methods that eliminate standing up movements) should be considered in such situations.
- b. *Making adjustments to ADL movements according to the degree of bed rest in patients with metastatic bone tumors (bone metastasis) and bone and soft tissue tumors*
Bone and soft tissue metastases account for a large proportion of cancer patients' metastases, and these metastases tend to affect the ADL. Bone metastases have a predilection for the spine, pelvis, ribs, and the proximal portions of the femur and humerus, and fractures tend to occur when the metastases are osteolytic. To prevent pathological fractures, care must be exercised during the early stage so that the sites of the metastases are not exposed to loads or twisting in the direction of rotation, and radiation therapy is often instituted. Whenever a strong possibility of fracture exists, the level of bed rest and "prohibited movements" should be confirmed with a physician as described in the following, and ADL and IADL should be proposed so that such movements do not occur.
- c. *Making adjustments to ADL movements for patients with edema (lymphedema or other forms of edema)*
When lymphedema or some other form of edema of the limbs progresses and the skin becomes fibrotic and hard, or when manifestations of hypoproteinemic edema or anasarca develop as the cancer progresses, inadequate flexing of the joints occurs as a secondary manifestation; consequently, the ROMs become limited, and body movements become difficult because of the increased weight of the hands and feet as a result of the edema. When an upper limb is edematous, the movements involved in changing clothes and getting washed become difficult. When a lower limb becomes edematous, the movements involved in changing clothes for the lower

half of the body and washing the lower limbs become difficult, and the movements involved in walking and climbing or descending stairs become difficult. Providing instructions regarding how to make adjustments to aspects of daily living so as not to aggravate lymphedema is important. When multilayer lymphedema bandaging (MLLB) is performed, adjustments to the bandaging may be required so as to facilitate the maintenance of the ADL and IADL and provide motivation, thereby increasing the therapeutic effect and avoiding any reduction in the quality of life, ADL, or IADL during treatment.

3. *Reducing spiritual and psychological distress*

The efficacy of occupational therapy (including rehabilitation) in alleviating spiritual and psychological suffering has long been reported.⁴⁷⁻⁴⁹ Symptoms, including their spiritual and psychological circumstances, should be identified, and it is important to strictly manage risk and introduce work activities in an individualized and flexible manner to reduce loss experiences, even if only slightly. In addition, when symptoms such as depression, anxiety, or apathy are present, the work task level should be set at a slightly lower to avoid causing fatigue as much as possible, and patients should be carefully observed for signs of fatigue. Tasks can be discontinued before they are completed, attractive tasks should be selected, and consideration should be given to the importance of patients being able to feel a sense of achievement or having a successful experience. Careful supervision of sharp objects, such as scissors and cutters, is also necessary to prevent suicides.

4. *Reducing social distress*

Many patients feel sad as a result of no longer being able to fulfill their roles at work or in the home in the same way that they did before becoming ill (role loss), and they may feel a sense of debt (sense of being a burden) toward being a burden on those around them. Such distress is particularly severe in generations that have many social roles. Methods that enable patients to resume even some of their roles can be a means of dealing with "role loss." When patients are members of what under normal circumstances would be the "caregiver generation," they may feel a sense of being a burden, such as feeling conscience-stricken just because they are receiving nursing care from those around them. If the patient is not experiencing distress, it is better to make adjustments within the scope of the patients' abilities in advance so that they are able to perform their own personal activities (ADLs) with as little assistance as possible.

For example, if a mother says, "I want to make delicious meals for my growing children," adjustments can be made to movements that can be performed in a wheelchair, and self-help devices can be introduced so that they are able to prepare food when they return home. By providing support so that food preparation methods are casually passed on to their children, patients can also play a role in handing down recipes to the next generation. It is also useful to implement group therapy within the facility with the aim of encouraging interpersonal exchanges, enabling

a sense of belonging and a sense of connectedness to be achieved, and enabling social roles to be reacquired based on exchanges with other people.

CONCLUSIONS/FUTURE ISSUES

For persons who are at the end-of-life stage, independence or a lack of disability may be defined as the ability to continue to live one's life with dignity, exerting control over one's care and maintaining functional independence in self-care activities as far as reasonably possible. Physical and occupational therapies can facilitate the patient's function at a minimum level of dependence regardless of life expectancy and can improve the quality of survival at the end of life, enabling the patient's life to be as comfortable and productive as possible. Therefore, there is little doubt that quality of life and the quality of the death experience are enhanced when physical and occupational therapists are part of a team of health professions supporting palliative care patients and their families.

However, some patients do not have access to rehabilitation services, either because of their needs that are unrecognized by frontline staff, because of a lack of allied health professionals who are adequately trained in the care of patients with cancer, or because of a lack of high-quality literature evidence. Therefore, it is necessary that all health-care professionals should receive training in rehabilitation needs assessment and that physical or occupational therapists should acquire knowledge about cancer and incorporate established techniques into cancer care. Furthermore, research is needed to explore the role, components, and outcomes of physical and occupational therapies.^{50**}

Key learning points

- Rehabilitation interventions should be an integral part of palliative care.
- Physical and occupational therapies enhance function and quality of life for seriously ill people and their families and address their psychological and spiritual needs through meaningful activities.
- Improved care results in meaningful and hopeful end of life.
- Referrals should be made early in the disease to provide symptom management and improve the patient's quality of life.
- Goals of physical and occupational therapies for palliative patients are based upon what is most important to them at the time of evaluation and are continually revised as their priorities change over the trajectory of their disease.
- Therapists use specialized skills to enhance communication, form compassionate bonds, and set goals which are realistic but do not take away hope.
- The measurement of function should be performance based and use objective measures.
- Research is needed to explore the role, components, and outcomes of physical and occupational therapies.

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B 専門家が答える遺伝診療上の疑問



2 遺伝学的検査の実際と患者・家族へのケア

Q19 遺伝学的検査で病的変異を認めた場合に、患者が落ち込んだりショックを受けてしまいませんか

遺伝子検査を受け、その結果を伝えられた後の心理的側面について検討された代表的な研究を、いくつか概観する。

Lerman ら¹⁾は、BRCA1 変異に基づく乳癌 / 卵巣癌家系を対象とした前向きコホート研究の中で、46 名の BRCA1 変異保有者、50 名の非保有者、および 46 名の検査拒否者の 3 群について、検査前後(ベースライン・検査結果開示 1 ヶ月後)での抑うつ症状の変化を評価した。その結果、ベースライン、結果開示 1 ヶ月後ともに、3 群すべてで抑うつ症状の程度は正常範囲内であったが、変異非保有者は保有者、拒否者と比較して、1 ヶ月後の抑うつ症状は有意な軽減を示していた。また、変異保有者、検査拒否者においても、抑うつ症状は増悪せず、変化を示さなかった。なお欧米の報告では、ハイリスク者の中で遺伝子検査を拒否する者の割合が比較的高いことが知られており、そうした拒否者の心理・社会的側面に焦点を当てた検討も行われている。遺伝性非ポリポーシス大腸癌(HNPCC)の家系 139 名を対象とした、遺伝子検査を受けるかどうかの意思決定に関する報告²⁾において、55 名(40%)が検査を拒否し、抑うつ症状のあることが検査を拒否することと有意に関連していることが示された。逆に、教育歴が高いことや以前に遺伝子研究に参加したことがあることが、検査を受けることと有意に関連していた。

HNPCC に関連した遺伝子結果開示後の心理的側面に関する研究では、Gritz ら³⁾の報告がある。遺伝子検査を受けた 155 名について、検査前、検査結果開示 2 週間後、6 ヶ月後、12 ヶ月後の抑うつ、不安、癌に対するおそれ(cancer worry)、心理的衝撃を評価尺度(質問紙)により評価した。その結果、すでに癌を発症している対象者については、変異の有無にかかわらず、すべての評価尺度得点において変化はみられず、正常範囲内を示していた。まだ癌を発症していない変異保有者については、抑うつ、不安、癌に対するおそれとも、その得点が結果開示 2 週間後には上昇したが、6 ヶ月後には低下していた。また、癌を発症しておらず変異もみられなかった対象者については、抑うつ、不安は経過の中で変化がみられず、癌に対するおそれは低下していた。さらに変異保有者については、癌を発症しているか否かにかかわらず、結果開示 2 週間後の心理的衝撃の得点は変異非保有者に比べて高くなっていたが、結果開示 12 ヶ月後には得点は低下するという結果であった。結果を通じて心理的負担の高かった対象者に関連する要因としては、ベースラインでの感情障害の存在、低い QOL、ソーシャルサポートの乏しさが有意な因子として抽出された。

わが国における研究では、村上、岡村ら⁴⁾の HNPCC を対象とした報告がある。対象は、各施設の遺伝相談外来を初診した者のうち、HNPCC の選択肢を呈示された 20 歳以上の者で、遺伝子検査の結果開示後 1 ヶ月が経過した時点で、遺伝子検査の結果を示されたことによる心理・社会的衝撃(うつ病、心的外傷、罪悪感)を半構造化面接により評価するというものであった。その結果、42 名に対して評価が行われ、うつ病や心的外傷の診断基準を満たした者はいなかつ

表 1 うつ病の診断基準

- ①抑うつ気分：気分が沈むあるいはすぐれない日が毎日のように続く
- ②興味または喜びの減退：今まで普通にできていたことがおっくうで、やる気が出ない
- ③食欲の減退：食欲がない、食べてもおいしくない
- ④不眠：寝付けない、途中で目が覚めて眠れない、朝早くに目が覚める
- ⑤焦燥または制止：イライラして落ち着かない、考えが前に進まない
- ⑥易疲労性：いつも疲れを感じている、疲れやすい
- ⑦罪責感：周囲の人に迷惑をかけているのではないかと悩む
- ⑧集中力の減退または決断困難：集中力が続かない、決断ができなくなる
- ⑨自殺念慮：生きていても仕方がないと考える

①または②のいずれかを含んだうえで(必須項目)、全9項目中5項目以上を満たし、それが2週間以上続いている場合にうつ病と診断

たものの、7%は軽いうつ状態を、12%は罪悪感を呈していたことを報告した。また、心理的負担に関連する要因としては、うつ病あるいはうつ状態の既往が有意な因子として抽出された。

以上、いくつかの研究結果について概説したが、これまでの報告の多くはここで示したように、遺伝子検査の結果開示後には、その結果がたとえ変異陽性であっても、またすでに癌を発症しているか否かにかかわらず、精神医学的対処を必要とするほどの心理的負担・衝撃は生じないとするものであった。また、たとえ結果開示直後は心理的負担やうつ状態がみられていても、時間の経過とともに軽減していくといった報告が大部分であった。この背景のひとつには、遺伝子検査の前後で適切な遺伝カウンセリングが実施されていることによると考えられている。しかし、精神疾患の診断はつかないもののうつ状態を呈する者や罪悪感を抱くものは何%かにみられ、特に、精神疾患の既往のある者、神経質な性格傾向の者、ソーシャルサポートの乏しいものにはその傾向が強いことが明らかとなっていることから、医療従事者は対象者の心理的反応を常に注意深く評価する必要があるといえる。

最後に、米国精神医学会による精神障害診断統計マニュアル(DSM-IV-TR)⁵⁾に基づくうつ病の診断基準を表1に示す。今回述べたように、遺伝子検査の結果が開示されてもうつ病を呈することは少ないといわれているが、うつ病は常に留意しておくべき、また見逃されやすい心理的負担である。癌の遺伝診療を行う場合も常にうつ病の可能性には留意し、うつ病を疑った場合には早目に専門医に紹介していただくことが重要と思われる。

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終末期を迎える方を理解するために

近年、がん患者の心身機能を含めた病状からの回復だけではなく終末期への対応として、理学療法をはじめとするリハビリテーションが積極的に行われるようになっており、その重要性が高まってきている。実際、われわれが日本医療機能評価機構の病院機能評価に認定された医療機関を対象に行った調査¹⁾では、1,045 施設中、がん患者に対してリハビリテーションを実施していた施設は 864 施設 (82.7%) であり、かかわっている職種として最も多かったのは理学療法士であり、実施内容としては歩行訓練 (92.1%)、筋力増強訓練 (88.9%) などが多いことが示された。また、がん患者に対してリハビリテーションを実施していなかった 181 施設においても、171 施設 (94.5%) はリハビリテーションの必要性を感じていると回答し、必要性を感じる場面として、「もう一度立って歩きたいという要求が患者からあったとき」「他人に頼らずトイレをしたいという要求が患者からあったとき」などが多くあげられるなど、終末期においてもリハビリテーションのかかわりの重要性が示唆される結果となった。

このように、臨床現場では多くのリハビリテーション従事者、特に理学療法士が終末期がん患者の治療にあたっていると思われるが、終末期がん患者には落胆、孤立感、疎外感、絶望などの通常の心理的な反応から、専門的な対応が必要な心理的問題がみられることがあることから、理学療法士は常に患者の心理状態に留意しておく必要がある。これらのなかでも、終末期がん患者にみられ、留意が必要とされる心理的問題の代表的なものは、適応障害、うつ病、せん妄である。これらの心理的問題はいずれも患者の quality of life (QOL) を低下させるだけでなく、理学療法を行ううえで障害となることもあることから、適切に評価し対応することが重要である。

本章では、まず積極的な抗がん治療が中止となり症状緩和中心の治療に移行する、すなわち終末期に入ることにに関する情報開示が行われた後に患者が呈する一般的な心理的反応について述べ、次いで留意すべき 3 つの心理的問題について概説する。最後に、終末期がん患者と接する理学療法士のメンタルヘルスの問題について触れる。

終末期を迎える患者の一般的な心理的な反応

積極的な抗がん治療が中止となり症状緩和中心の治療に移行するといった情報開示は、患者にとって最もつらい知らせの 1 つとなる。こうした悪い知らせ (bad news) が告げられた後に患者が示す一般的な心理的反応を理解しておくことは重要である。まず最初にみられる反応は、ショックである。告げられた内容を信じようとしないうちに、「そんなはずはないだろう……」と一時的に否認したり、また「もうダメなんだ……」と絶望感を感じたりす

ることで特徴づけられる。後になって、「頭が真っ白になって、まるで自分自身に起こっていることではないかのような感じだ」と述べることもある。それから少し時間が経過すると、今度は気持ちが沈んだり、不安になったり、周囲から孤立したように感じたり、あるいは眠れなくなったり食欲がなくなったり、といった症状が交互に何度もやってくる時期がくる。些細なことにドキドキしたり、ビクビクしたりといった症状がみられることもある。不安が強く集中力が低下しているために、同じことを繰り返し尋ねる、といった行動がみられる時期でもある。しかし、2週間を過ぎたころから徐々に現実の問題に直面できるようになる。すなわち、「残された時間をどのように過ごそうか」とか「自分がいなくなった後のことを考えておかなければ」といった見方もできるようになる。そして、100%健康なときと同じ気持で生活していくことは難しいにしても、徐々に気分は安定していくといわれている。

以上のように、終末期といっても、がん患者が診断や再発などの悪い知らせを告げられた際に呈する一般的な心理的反応と大きく変わるものではないが、終末期がん患者に特徴的な心理的負担として、「見捨てられることへの不安」があるといわれている。したがって、これから死を迎えようとする「人」が「終末期患者」として特別視されないための十分な配慮が必要である。

対応・留意を必要とする心理的問題

1 適応障害

1) 評価とスクリーニング

診断基準によると、適応障害とは「はっきりと確認できるストレス因子に反応して、情緒面または行動面の症状が出現」するもので、予想されるより反応の程度が強いか、または日常生活から社会活動に及ぶ社会的機能に支障をきたすときに用いられる。したがって、その基準はあいまいであり、気分の障害ではあるが、うつ病をはじめとする他の診断がつかないときの“ごみ箱的診断”として使用されがちである。しかし一方で、そのために特異的な精神疾患としてとりあげにくいさまざまな精神症状を拾いあげることができるという利点もある。わが国の終末期がん患者を対象とした面接調査では、適応障害は16%でみられたと報告されている³⁾。

適応障害のスクリーニング方法として、最近では「つらさと支障の寒暖計」(図1)がよく用いられている。原著者ら^{4,5)}によると、適応障害もしくは次に述べるうつ病と、精神医学的な診断がつかない症例を区別するためのカットオフ値は、つらさの点数が4点以上、かつ支障の点数が3点以上で、感度0.82、特異度0.82であったと報告されている。

2) 対応

原則的には理学療法を中断あるいは中止する必要はないと思われる。しかし、次の「うつ病」に準じた治療が必要となることもあるため、専門家に相談あるいは紹介するのが望

1. この1週間の気持のつらさを平均して寒暖計の中の最も当てはまる数字に○をつけて下さい

2. その気持のつらさのためにこの1週間どの程度、日常生活に支障がありましたか？

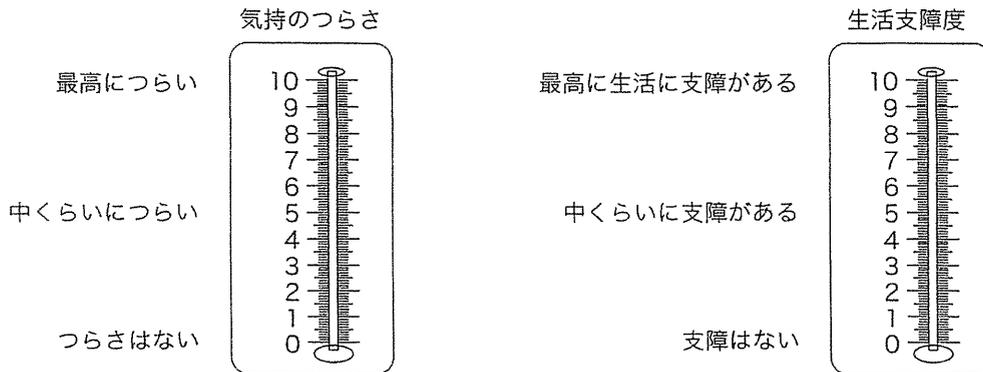


図1 つらさと支障の寒暖計
(http://pod.ncc.go.jp/documents/DIT_manual.pdf より引用)

ましい。ただし適応障害の場合には、現在つらいことや不安に思っていることを表出し、医療者にその苦しみを伝えることができたと感じることで症状が軽減することがよくある。したがって、理学療法を行っていくなかで、心理的側面にも留意しながら接することが、適応障害の治療となっていることに気づくことが重要である。

2 うつ病

1) 評価

うつ病の診断基準を表1に示すが、がん患者、なかでも終末期がん患者のうつ病診断は難しいといわれている。それは、診断基準に含まれている食欲減退、不眠、易疲労性といった身体症状は、終末期にはよくみられる症状であるためである。したがって、終末期だから、あるいはがんが進行しているのだからこうした症状があっても当然とみなされ、終末期がん患者のうつ病を過小評価される傾向が強い。しかし、わが国の終末期がん患者を対象とした面接調査では、うつ病は7%でみられたと報告されている³⁾。これらの身体症状によるうつ病評価の混乱を避けるために、これまでさまざまな診断基準が考案され、有用性の検討が行われ

表1 うつ病の診断基準

- ①抑うつ気分：気分が沈むあるいはすぐれない日が毎日のように続く。
- ②興味・喜びの減退：今まで普通にできていたことがおっくうで、やる気がでない。
- ③食欲の減退・体重減少：食欲がない、食べてもおいしくない。
- ④不眠：寝つけない、途中で目が覚めて眠れない、朝早くに目が覚める。
- ⑤焦燥または制止：イライラして落ち着かない、考えが前に進まない。
- ⑥易疲労性：いつも疲れを感じている、疲れやすい。
- ⑦無価値感・罪責感：周囲の人に迷惑をかけているのではないかと悩む。
- ⑧思考力・集中力の減退または決断困難：集中力が続かない、決断ができなくなる。
- ⑨自殺念慮：生きていても仕方がないと考える。

①または②のいずれかを含んだうえで(必須項目)、全9項目中5項目以上を満たし、それが2週間以上続いている場合にうつ病と診断される。

(APA: DSM-IV-TR より)

てきた。しかし、個々の症状についての原因は問わず、あてはまる症状が存在した場合は診断項目に数える、すなわちうつ病を過小評価せず見逃しを減らすことのほうが、臨床的に重要であるというのが現在の考え方である⁶⁾

2) うつ病診断の重要性

うつ病を的確に評価し、対応することがなぜ重要か、具体的な症例を提示してみる。

■症例■

再発乳がんがフォローを受けていたが、終末期の段階に入り、症状緩和中心のケアが行われ、症状コントロールはまずまずの状態であった (performance status=4)。しかし徐々に不眠が出現し持続。さらにしばらくすると、「もう生きていても仕方がない。楽になりたい。」という発言がみられ、表情も乏しくなってきた。眠剤の投与が行われたが効果はなく、上記状態が持続するため、精神科を紹介された。診察の結果、うつ病と診断され少量の抗うつ薬で治療された結果、睡眠がとれるようになり、表情も穏やかになっていった。

本症例のように、終末期がん患者が希死念慮を訴えることは決してまれではなく、その背景にうつ病が存在している場合があることはよく知られている。しかし治療を行えばうつ病は改善し、終末期といえども気分や病気への向き合い方が変わる可能性は十分あることから、うつ病を常に考慮し、患者の苦痛を理解することが不可欠といえる。

3) スクリーニング

うつ病を簡便にスクリーニングする手段として、上述した「つらさと支障の寒暖計」をはじめ、さまざまな質問紙や評価尺度が紹介されており、がん患者のうつ病の存在を示唆する指標としての利用価値は高い。しかし、それらを施行する前段階としてまず必要なのは、患者に存在する精神的負担について医療者が関心をもち、それについて患者と話し合うことである。

Chochinov ら⁷⁾は、終末期がん患者 197 例に対して 13 項目からなる簡易抑うつスクリーニング尺度、および抑うつ気分のみを尋ねることを実施したところ、「気分はいかがですか？ 落ち込んだりしていませんか？」と尋ねることがうつ病のスクリーニングとして最も有用であったことを報告している。患者の前に立ったときに、「調子はどうですか？」と尋ねた後で、もう一言、「気分はいかがですか？」と付け加えることは、臨床に大きな負担をかけることなく行うことができ、しかも今すぐにでも実践できる、うつ病を見逃さないための簡便かつ有効な手段となると思われる。

表2 パフォーマンスステータス (Performance Status : PS)

全身状態の指標の一つで、患者さんの日常生活の制限の程度を示します。

- 0: まったく問題なく活動できる。発症前と同じ日常生活が制限なく行える。
- 1: 肉体的に激しい活動は制限されるが、歩行可能で、軽作業や座っての作業は行うことができる。例: 軽い家事、事務作業
- 2: 歩行可能で、自分の身のまわりのことはすべて可能だが、作業はできない。日中の50%以上はベッド外で過ごす。
- 3: 限られた自分の身のまわりのことしかできない。日中の50%以上をベッドか椅子で過ごす。
- 4: まったく動けない。自分の身のまわりのことはまったくできない。完全にベッドか椅子で過ごす。

(ECOG (米国の腫瘍学の団体の1つ) が決めた、Performance Status (PS) の日本臨床腫瘍研究グループ (JCOG) による日本語訳、国立がん研究センターがん情報サービス (http://ganjoho.jp/public/qa_links/dictionary/dic01/Performance_Status.html) 参照)

4) 対応

原則としては理学療法を中断し、うつ病の治療を優先させるべきである。しかし、患者とのかかわりを継続させるという意味で理学療法を行う場合には、うつ病のために意欲、集中力、思考力が低下している状態であることを十分認識したうえで対応する必要がある。

適応障害とうつ病へのアプローチとしては、精神療法と薬物療法が中心となる。精神療法については近年、さまざまな試みが行われ、その有効性が報告されてきている。しかし、がん患者に対する精神療法の基本は「支持的精神療法」といわれている。これは、「病気の受容や死の受容を目指すのではなく、病気によって生じた役割変化、喪失感、抑うつなどを軽減することを目標とする。個々の患者における病気の与える意味を探り、理解し、これまで過去に行ってきたその人なりの病気との取り組み方で、困難を乗り越えていけるよう支えていく。このためには治療者はまず、患者が今まさにここで感じている気持 (here and now)、特に恐れ・不安の表出を促し、それらを支持・共感し、非現実的な情報を与えるのではなく、現実的な範囲で保証を与えていく。苦しみが今まさに理解されつつあると伝わったとき、治療となる」といったアプローチであり、決して死の受容を目指すのではなく、患者の感情の表出を促し、それを傾聴し支持することが基本となっている。終末期がん患者に対しても、支持的精神療法を基本としたかかわりは重要と思われる。

3 せん妄

1) 評価とスクリーニング

せん妄は、進行期から終末期に多くみられる器質性精神疾患であり、軽度の意識混濁に精神運動興奮、錯覚や幻覚などの認知障害を伴う「意識」の障害である。意識が障害されることから、多彩な精神症状が出現する。せん妄の典型例では、症状の日内変動(特に夜間に症状が増悪)、注意の集中・維持が困難であることが特徴的である。評価にあたってはこうした症状とともに、見当識、計算力などの認知機能を評価することが重要である。がん患者におけるせん妄の有病率は、全病期を通じては4~27%程度と報告されている⁸⁾が、身体状態が増悪し終末期になるにつれ上昇することが知られている。特に終末期の場合には、活発に活動するタイプの過活動型せん妄よりも、活動量が低下するタイプの低活動型せん妄の頻度が高いといわれている。

せん妄のスクリーニングには、認知機能の客観的な評価法であるMini-Mental State Examination (MMSE) が有用であるとする報告が多い⁹⁾が、実際の臨床の場面で

表3 せん妄のタイプ別による評価

過活動型	低活動型
以下の2つ以上 ・身体的運動量の増加 ・活動コントロールの喪失 ・落ち着きのなさ ・徘徊	以下の4つ以上。◎のどちらかが必須 ◎活動量の低下 ◎行動の速さの減弱 ・周囲に関する認識の減少 ・会話量の減弱 ・会話の速さの減弱 ・無関心

混合型：活動型、低活動型の双方の基準を満たす。

閾値以下：活動型、低活動型の双方とも基準を満たさない。

(Meagher D et al : A new data-based motor subtype schema for delirium. J Neuropsychiatry Clin Neurosci 20 : 190, Figure 1, 2008 より引用)

は、表3に示すような臨床基準を用いるほうが参考になると思われる⁶⁾。特に、終末期がん患者のせん妄には低活動型が多く、しかも低活動型せん妄は見逃されやすいことから、その存在を常に意識しながら症状を観察していくことが必要である。

2) 対応

うつ病と同様、原則としては理学療法を中断し、せん妄の治療を優先させるべきである。しかし、理学療法でのかかわりが必要と考えた場合には、“意識障害”の状態であることを十分認識したうえで対応する必要がある。

せん妄への対応としては、まず原因の同定とその治療が優先される。ただし、治療により回復可能なのか回復困難なのかを見極め、ケアのゴールをどこに定めるのかが重要である。薬物療法については、一般的なせん妄治療に準じて行う。また上記に加え、環境調整や家族支援、病棟スタッフへの支援・教育も必要である。終末期せん妄への対応をまとめたものを表4に示す。

表4 終末期せん妄への対応

- ・終末期せん妄の56%は原因不明で、3分の2は回復せず死に至るという報告がある。
- ・対応に関して、明確なコンセンサスは得られていない。
- ・チームで相談し、目標を共有する。
- ・不可逆的となりうることに對して、あらかじめ見通しを立て、家族に伝える。
- ・家族と医療者が目標を共有する。
- ・適切なケアが行われているか否か、多職種の視点で繰り返し見直す。

理学療法士自身のメンタルコントロール

終末期がん患者のケアに携わっているスタッフは、高い死亡率、激しい衰弱と容貌変化、緩和できない症状(難治性疼痛、呼吸困難、倦怠感)といった、がん医療特有の要因に直面することで、常に強度のストレス状態にあるといわれている。理学療法士も同様であり、回復を目指して懸命に理学療法を行ってもADLは徐々に低下していくことから、何のために治療をしているのかがわからなくなる、という悩みを聴くことがある。さらに、怒り、不安、抑うつといった患者の態度や心理的反応への対処の困難さ、すなわちがん患者とのコミュニケーションの難しさも、スタッフのメンタルヘルスに大きな影響を及ぼすと考えられている。こうしたストレス状態から生じる精神的問題の1つにバーンアウト(burn out: 燃え尽き)がある。バーンアウトはがん医療に従事するスタッフのメンタルヘルスを考えていくうえで非常に重要、かつ対処していかなければならない問題であることから、ここでは、このバーンアウトに着目し、がん医療スタッフにみられるバーンアウトの特徴や対応について述べる。

1) バーンアウトについて

1) 定義

バーンアウトの概念は1970年代に米国で、医療従事者をはじめ対人関係を扱う専門職の人々に対するメンタルヘルスの領域で注目されるようになった。Freudenberger¹¹⁾は、バーンアウトを「自分が最善と信じて打ち込んできた仕事、生き方、対人関係の持ち方が、

まったくの期待はずれに終わったことによってもたらされる疲弊のありさま」と定義している。また Maslach¹²⁾ は、「援助的活動を行っているうちに精神的活力を使い果たしたために起こる症候群で、心身の極度の疲労と感情の枯渇、自己嫌悪、思いやりの喪失などからなる」としている。現在はこの Maslach の定義に基づき、医療者にみられるバーンアウト症候群を、「長期間にわたって患者に援助を行う過程で、心のエネルギーが絶えず過度に要求された結果、極度の心身の疲労と感情の枯渇をきたすことを主とする症候群」と定義することが多い。

2) 症状

以下の3つの症状で特徴づけられる¹³⁾。

- ・情緒的消耗感 (emotional exhaustion : EE) : 体も気持も疲れはてた
- ・脱人格化 (depersonalization : DP) : 患者に対する細かい心配りが面倒
- ・個人的達成感の限界 (sense of low personal accomplishment : PS) : 何のために仕事をしているのか?

バーンアウトの進行とともに、徐々に情緒的消耗感→脱人格化→個人的達成感の限界と、症状が加わっていくといわれている。

3) バーンアウトにより生じる問題点

バーンアウトにより、スタッフ個人さらには患者に対してさまざまな悪影響が生じるといわれている。スタッフ個人については、不安、焦燥感、気分の波、不眠といった症状が出現するだけでなく、うつ病あるいはアルコールや薬物の依存といった、診断名がつくほどの状態にまで陥ることがある¹⁴⁻¹⁷⁾。特に、うつ病となった場合にはすべてに自信がなくなり辞職をしようとしたり、最悪の場合は自殺にまで追い込まれることがある。このように、バーンアウトはスタッフ自身の生活の質 (quality of life : QOL) を低下させることになる。一方、バーンアウトは医療にも影響を及ぼすことがある。すなわち、バーンアウトによりケアが機械的で表面的となり、患者ケアの質や安全性の低下につながるとの指摘がある^{14, 17)}。さらに、安楽死を支持する医療者の背景要因として、バーンアウトの強さが有意な因子として抽出されたという興味深い報告もある¹⁸⁾。

4) バーンアウトへの対応

バーンアウトの予防や対策にあたっては、セルフケアだけではなく、医療チーム全体として取り組み、かかわっていくことが重要であるといえる。

a. 医療チームとして

医療チームのかかわりとして重要なことを以下にまとめた。

- ・オープンコミュニケーション : 仕事上の悩み、葛藤などを気軽に話しあえる雰囲気を作る
- ・非言語的なコミュニケーション : “思いやる”あるいは“察する”
- ・症例カンファレンスの実施

特に、最後の症例カンファレンスの実施は重要である。バーンアウトの原因になりやすいといわれている、患者とのコミュニケーションがうまくいっていない場合 (対応が難し

い患者の場合が多いと思われるが)など、カンファレンスを通して皆でどのように接していけばよいかを共有することで、個人の心理的負担は軽減できると思われる。

b. セルフケアとして

セルフケアとして重要なことを以下にまとめた。

- 患者のためにとる時間に対して自分のためにも十分時間をとること(良い意味で利己的になることが必要)
- 適度な運動やリラクセスの時間をとること
- 自分自身をサポートしてくれる人(できれば心の問題について相談できる専門家も)をみつめておくこと
- 自分自身を必要不可欠であると思わないこと
- 限界を認めること(誰も完全ではないのだから)
- コミュニケーションスキルを身につけること

特に、コミュニケーションスキルについては、がん医療従事者のバーンアウトに関連する要因を検討した結果で、患者との関係(コミュニケーション)が良好でないことが有意な因子として抽出された報告もある。トレーニングを受けることなどによって、スキルを身につける努力をすることが重要である。

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