Neurorehabilitation

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Abstract

People affected by brain tumours (BTs) can experience a wide range of symptoms and disabilities, such as reduced mobility, cognitive and psychological problems, difficulties with self-care and relationship and work issues, which can result in reduced ability in daily life activities and in performing (or maintaining) usual family and social roles, with a substantial impact on quality of life.

Neuro-oncological rehabilitation refers to the process of assisting a person who has become disabled as a result of tumour (or therapies) to improve symptoms and maximise functional independence, activity (e.g. walking) and participation (e.g. employment, reintegration into social and domestic life), within the limits of the persisting impairment. As for other diseases/impairments, disabilities caused by BTs can be expressed within the conceptual framework of the International Classification of Functioning, Disability and Health (ICF), which was developed by World Health Organization (WHO) to describe health and the multidimensional health-related concerns of individuals. Symptoms and disabilities may be addressed through a "multidisciplinary rehabilitation" delivered by a team of different healthcare professionals working in an organised manner. Nurses assume a pivotal role for the creation of a supportive environment for rehabilitation as most of nurses' activities represent essential rehabilitative skills. Rehabilitation nurses also provide patients and caregivers with education and emotional support and act as a link between patients and families and the different healthcare settings. The complexity of knowledge and skills required to

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provide such comprehensive care illustrates the need for increasing specialisation in neuro-oncology to strengthen and raise the nurses' professional profile.

Keywords
Brain tumours · Neurorehabilitation · Neuro-oncology · Functional outcome · Nurse

Abbreviations

ADL	Activities of daily living
ARN	Association of Rehabilitation Nurses
BT	Brain tumours
CNS	Central nervous system
EORTC	European Organisation for Research and Treatment of Cancer
GBM	Glioblastoma multiforme
HGG	High-grade gliomas
HRQOL	Health-related quality of life
ICF	International Classification of Functioning, Disability and Health
KPS	Karnofsky Performance Status
OT	Occupational therapy
PNS	Peripheral nervous system
QoL	Quality of life
WHO	World Health Organization

Learning Outcomes

- To understand why neurorehabilitation becomes really important in achieving the highest degree of functional recovery and autonomy for glioma patients.
- To gain knowledge and insight into varying rehabilitation tools and knowing the difference between different concepts and types of neurorehabilitation—be it cognitive, functional or sensory-motor.
- To provide caregivers with support, education and coping strategies.
- To explore the crucial, specific neuro-rehabilitative roles and activities nurses undertake on a daily basis, which represent essential rehabilitative skills.

9.1 Introduction

Brain tumours (BTs) represent a heterogeneous group of lesions of the central nervous system (CNS) in which can be recognised primary tumours and brain metastases. While primary tumours present a lower prevalence (it is estimated that 1/5000 adults will suffer from a primary brain tumour), the incidence of brain metastases has recently increased due to the substantial development of oncologic therapies, with a predominance in the sixth and seventh decades of life.

The primary adult tumours include meningiomas, schwannomas, primary CNS lymphomas and gliomas of the cerebral hemispheres (i.e. glioblastoma multiforme, anaplastic astrocytoma, low-grade astrocytoma and oligodendroglioma). In adults, high-grade gliomas (HGG), WHO grade III or grade IV, are the most common primary brain tumours, and glioblastoma multiforme (GBM) is the most frequent glioma.

BTs represent about 2% of the total incidence of cancer that will presumably increase in the future since the life expectancy is outspreading; the overall incidence is the same in males and females, but GBM is more frequent in men, while meningiomas and schwannomas occur more often in women.

Median overall survival in patients with GBM remains poor, 15 months for newly diagnosed GBM and 5–7 months for recurrent/relapsed GBM.

Given the poor prognosis of many BTs, the primary objectives of the therapies are to reduce morbidity and restore or preserve neurologic functions and the ability to perform daily activities as long as possible. Nowadays therapeutic progress in fact is transforming many of these diseases either into chronic processes or that require long-term treatments; however current forms of available treatment (i.e. chemotherapy, radiotherapy, surgery) often determine significant consequences on functioning and quality of life (QoL) of individuals with cancer.

Lastly, as far as public health is concerned, the impact of BTs is significant in spite of their low incidence because they include high direct costs (diagnostic resources, high complexity treatments and rehabilitation) and high unforeseen costs (labour leave, family and social expenditures). A population-based comparison of cancer survivors with matched controls found a substantially increased burden of illness in cancer survivors, manifested in days lost from work, inability to work, poor general health perception and the need for help with daily activities. Furthermore, compared with age-matched controls, cancer survivors reported poorer health outcomes, decreased functioning and higher levels of burden across multiple domains. Interestingly, these decrements were consistent across tumour sites and time since diagnosis [1]. Additionally, these concerns and functional decrements appear to persist across age categories.

These data suggest that cancer patients experience an elevated burden of illness, and this relationship appears to exist irrespective of age, tumour site or time since diagnosis.

9.2 Brain Tumours and Disabilities: Rehabilitation Needs

Neuro-oncological patients are prone to a number of neurological symptoms, both sensory-motor and cognitive, due to the primary tumour itself (*mass effect*) or to the side effects of the treatments.

The most common symptoms induced by BTs may include headache, nausea and vomiting and drowsiness during the day and are commonly related to high intracranial pressure, whereas local tumour effects might result in focal neurological problems, such as paresis, ataxia, dysphagia, sensory loss, visual-perceptual deficits,

Table 9.1 The most common neurological symptoms in primary brain tumours

Cognitive deficits	80%
Motor deficits	78%
Fatigue	40–70%
Visual-perceptual deficits	53%
Sexual dysfunction	>50%
Sensory loss	38%
Bowel/bladder impairment	37%
Cranial nerve palsy	29%
Dysarthria	27%
Dysphagia	26%
Speech disorders aphasia	24%
Ataxia	20%

cognitive deficits and seizures [2] (Table 9.1). Changes in personality and behaviour, as well as mood issues (anxiety and depression), also frequently occur [3].

Also cancer-related fatigue, low energy and weakness are frequent and extremely distressing symptoms among BT patients that may be one of the most challenging barriers to effective rehabilitation [4]. Fatigue is commonly considered to have a multifactorial basis, including several physical and mental factors such as pain, anxiety, deconditioning, sleep problems, anaemia, malnutrition, infection, cognitive disturbance as well as the type of treatment. Therefore, all patients should be evaluated about potential fatigue with treatment, and potential interventions should be considered. Pharmacologic treatments for fatigue can include medications to optimise sleep, mood and pain control, while among non-pharmacologic treatments exercise, behavioural and coping strategies, high-protein diet, adequate hydration and management of anaemia have been proposed.

Symptom severity fluctuates during the course of the disease, and patients may experience a temporary improvement when responding to treatment or a progressive neurological and functional decline as the disease progresses.

Physical and neurological functioning can also be strongly affected by the side effects of treatments. In recent decades, in fact, therapeutic advances in oncology have prolonged the survival of individuals, also those with CNS tumours, even though these individuals are often left with residual neurological deficits [5]. The CNS and peripheral nervous system (PNS) in fact become “target” organs of the therapies, which in turn determine a number of side effects to be considered within the global evaluation of the patient: postsurgical morbidity; acute, subacute and late radiation effects on the normal brain; chemotherapy-induced toxicity; high-dose corticosteroids; and anticonvulsants can all produce adverse effects [4, 6] (Fig. 9.1a–c).

Overall, these symptoms cause functional impairments similar to those seen in patients commonly submitted to rehabilitation programmes [7] and have a considerable impact on patients’ daily life, hindering their ability to function independently and to maintain usual family and social roles, influencing ultimately their QoL as well as the QoL of their family members. Relatives bear the burden of care, which disrupts family life. Families experience initial chaos and confusion followed by a heavy burden of care and feelings of helplessness and isolation, with a negative impact on their well-being [8].

At this point the role of rehabilitation becomes really important to favour the highest degree of functional recovery and autonomy for patients and to provide caregivers with support, education and coping strategies.

The plasticity of CNS and its capacity to reorganise itself after damage represent the foundation of any rehabilitative intervention. Since Hebb's suggestion that

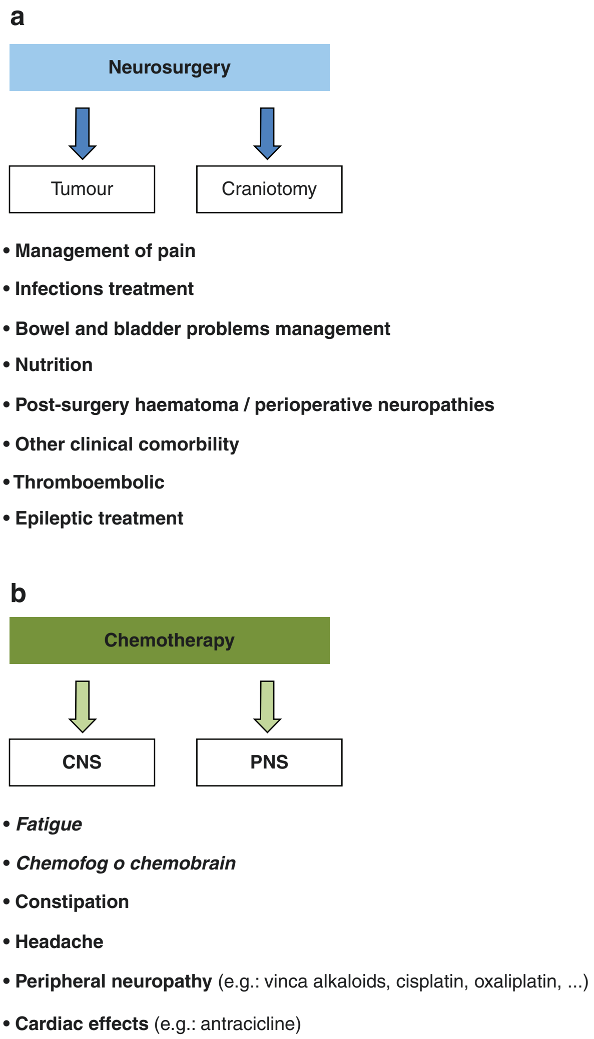

Fig. 9.1 Main side effects of therapies for brain tumours on central and peripheral nervous system

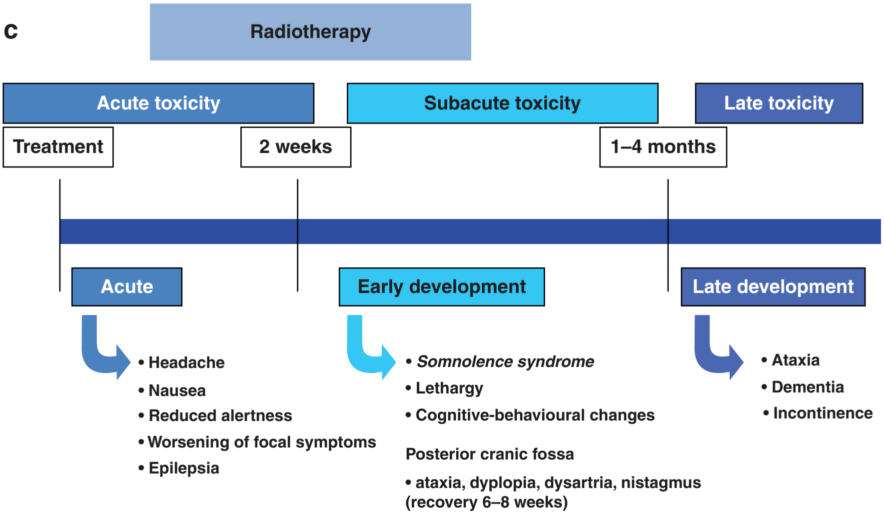

Fig. 9.1 (continued)

neuronal cortical connections can be remodelled by experience, evidence derived from animal studies and new imaging techniques increased our understanding of neurological recovery and the role of rehabilitation therapies in promoting such recovery [9]. The neurobiological mechanisms of plasticity and spontaneous recovery include cell genesis, functional plasticity and structural adaptations, such as axonal sprouting and synaptogenesis. Overcoming the old dogma that there is a fixed number of neurons in the adult mammalian brain that cannot be replaced when the cells die, the studies in the last century showed that in some areas (olfactory bulb, *gyrus dentatus* of the hippocampal formation, subventricular zone), neurogenesis (regeneration) may occur. Moreover, connections between neurons in the nervous system are continuously being altered depending on environmental and behavioural stimulation and responses to bodily injury. Through axonal sprouting and synaptogenesis, the brain has the ability to form new functional connections after it has experienced a perturbation or injury [10].

The nature and timing of these mechanisms are revealed by the course of motor recovery observed in patients (mainly stroke survivors), most of whom reach their recovery plateau within the first 3–6 months. However, considering some prognostic factors (type of disease, age, lesion site, neurological impairment and performance status), it is widely accepted that improvements can continue for years, through rehabilitation-guided learning-dependent processes.

9.2.1 The "Total Pain": A Global Concept

Literature data reported that between 30% and 50% of cancer patients experience significant pain due to disease progression or therapeutic interventions with a prevalence of 90% in advanced stages. Along with other factors, such as young age, recent diagnosis and tumour aggressiveness, pain was significantly associated with a low level of functioning and a reduced QoL.

The neurophysiology of cancer pain is a striking example of the complexity of pain as it involves chemotherapy-induced neuropathic pain; iatrogenic radionecrosis (cell deaths due to radiotherapy effects); postoperative pain; inflammatory, ischaemic and compressive phenomena; and direct tumour invasion of tissues including nerves and plexuses with a neuropathic component [11]. However, it is not purely a physical experience but involves various other components of human functioning, including psychological, social and spiritual components as well as social relationships, and it is often referred to as “total pain” to underline the global nature of pain within a “whole-person” framework [12]. The combination of these elements is believed to result in a comprehensive suffering experience that is individualised and specific to each patient’s particular situation. Albeit so widespread, pain remains one of the most difficult diagnostic and therapeutic problems in oncology, and literature evidence suggests that an inadequate assessment is far too common. Some nurses may rely only on their own observation to assess pain, without asking the patients to describe their pain; however, this approach does not allow to adequately evaluate a patient’s “total pain” because patient’s perspective or spiritual, psychological and social aspects are ignored. Moreover, the complexity of treating patients with “total pain” may be exacerbated by the patients’ inability to identify exactly which component is causing pain, as in most cases they may be unaware of the fact that their pain experience results from a combination of factors.

It therefore follows that pain assessment must include aspects that go beyond the mere physical manifestations of pain in order to effectively manage oncological pain and that the treatment of only physical symptoms, without a wider exploration of the other dimensions of the patient’s suffering experience, results in an incomplete and often inappropriate pain regimen [13]. Psychological support for patients and families confronted with a life-threatening illness is often overlooked and can be even more undermined when physical pain becomes the main focus of treatment plan. Family meeting including patient, family and health professionals can be an effective tool to overcome these difficulties as all members of the family may be heard and understood; may share feelings, concerns and expectations; and may support one another. Communication represents an essential intervention that allows health professionals to understand patients and family needs to provide appropriate interventions.

9.3 Taking Care of the Person with Brain Tumour: The ICF Framework

Owing to improved surveillance and treatment methods, survival rates of cancer have improved over time creating the need to recognise and attend to a variety of concerns unique to cancer survivorship. In order to identify such potential concerns, it may be useful to utilise an overarching framework to guide the provision of care. As for other diseases/impairments, disabilities caused by BTs can be included within the conceptual framework of the International Classification of Functioning, Disability and Health (ICF), which was developed by the World Health Organization to provide a framework to describe health and the multidimensional health-related concerns of individuals [14].

The ICF framework is increasingly being used in the rehabilitation field, but it has been utilised for a diverse array of purposes in the field of oncology, evaluating functioning in persons with cancer, assessment in oncology rehabilitation, assessing the outcome measures and comparing the primary concerns of health professionals with those of their patients.

Briefly, the ICF model shifts the focus of disablement from cause to impact, from disability to health and function and from a static to a dynamic process.

Using a global approach to the person named *biopsychosocial model*, the ICF defines three domains of human function: *body function and structure*, *activity* and *participation* (Fig. 9.2). *Body function and structure* refers to the anatomical and physiological function of the body systems and is categorised into subdomains. Deficits in this domain are defined "impairments" (e.g. muscle weakness, spasticity, restricted joint motion, pain, visual deficits, seizures and poor cardiorespiratory fitness).

The *activity* describes the ability of a person to perform specific tasks such as bathing or showering, dressing and feeding; reductions in the activity domain are named "limitations".

The *participation* domain describes the ability of a person to be involved in life situations. Participation restrictions describe the reduced ability of a person to maintain normal role functions in the person's environment, where different factors can

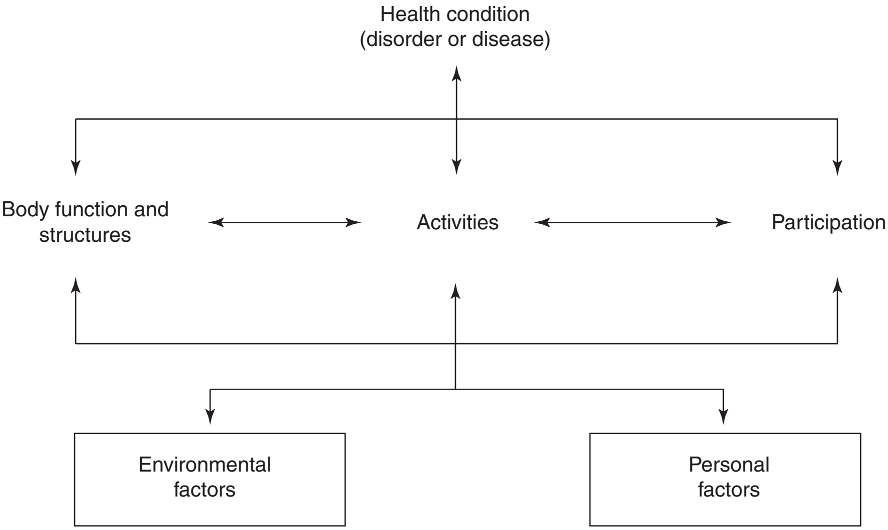

Fig. 9.2 The International Classification of Functioning, Disability and Health. Reproduced by the beginner's guide developed by the World Health Organization (*downloaded from*: http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf)

act as barriers or facilitators. For BT patient's physical, cognitive and psychological factors may represent barriers to social integration. In the ICF model, health conditions, personal factors and the environment interact dynamically across the three domains of body function to help determine whether disordered function results in disability (e.g. if a cancer treatment, such as chemotherapy, causes the development of peripheral neuropathy and ankle weakness, the patient may have a limited ability to walk "limitation" and may require long-term use of an ankle brace).

The ICF framework seems to be a useful model for describing global function in patients with a cancer diagnosis [15]. In recent years there has been increased use of the ICF in clinical settings, including ICF checklists to identify patient-reported problems in both acute and chronic conditions, and the basis for defining a dedicated core set was described [16]. The development of ICF Core Sets provides clinicians and researchers with comprehensive but concise measurement categories that describe a patient's global function from a biopsychosocial view. Some ICF Core Sets have been developed for patients with head and neck cancer and breast cancer.

The interaction among cancer as a modification of the health condition, impairments in body function and structure, activity limitations and participation restrictions in the context of the person and the environment is relevant to define an effective oncology rehabilitation intervention. Compensatory strategies, adjusting goals and expectations, educating friends and family and accepting support from others, facilitate social reintegration throughout the trajectory of living with brain tumour.

9.4 The Multidisciplinary Approach

Rehabilitation was defined as "a problem-solving educational process aimed at reducing disability and handicap (participation) experienced by someone as a result of disease or injury" [17].

For persons affected by BTs, rehabilitation can be challenging because, as previously described, they can present with various combinations of symptoms, such as physical, cognitive, psychosocial, behavioural and environmental issues which can substantially impact their QoL and that need to be addressed through "multidisciplinary rehabilitation". Multidisciplinary rehabilitation programmes assume that besides the anatomical or physiological problem, psychological factors such as fear, anxiety and mood disturbance may amplify symptoms; similarly, social/environmental factors such as physical job demands, workplace and social issues may worsen disability. These insights have led to the design of interventions that address multiple factors, typically involving a combination of physical, psychological, social and/or work-related components, which are delivered by a team of clinicians with different skills [18]. Therefore, multidisciplinary rehabilitation can be defined as the coordinated delivery of multidimensional rehabilitation interventions provided by two or more disciplines (i.e. nursing, physiotherapy, occupational therapy, social work, psychology and other allied health), in conjunction with medical professionals (oncologist, rehabilitation, surgeon, palliative physician), which aims to improve patient symptoms and maximise functional independence and participation (social integration) using a holistic biopsychosocial model of care, as defined by the ICF.

A multidisciplinary approach provides patients with skills needed to manage their own care to improve their coping ability, knowledge base and QoL. It prioritises patient-centred care and focuses on person's functions and disabilities, using a goal-based functionally oriented approach that is time-based. Specifically, in order to engage in effective patient-centred care, personal factors such as an individual's experiences, coping style, self-efficacy, attitudes, values, preferences and knowledge are relevant factors for consideration, and the patients (as well as family or carer) are active participants in the goal setting process. The content, intensity and frequency of therapy in multidisciplinary rehabilitation can vary, as programmes are individualised according to clinical needs (e.g. physical reconditioning, task reacquisition strategies, cognitive and behavioural therapy, vocational and recreational programmes and psychological support).

Although not conclusive and with a "low level" of evidence, preliminary studies seem to support the benefit of multidisciplinary rehabilitation in reducing disability in people with BTs: persons in the multidisciplinary rehabilitation group in fact showed a greater improvement in their functional abilities (e.g. continence, mobility) and cognitive functions compared with standard care [19].

Given these general but essential assumptions, two main aspects make the neuro-oncological rehabilitation particular and need to be underlined: first, the "limitations" due to life expectancy and the imposition upon health professionals to provide flexible clinical choices, with frequent reassessments and adjustments of the rehabilitative projects and programmes [5], and second, the "frailty" of neuro-oncological patients, due to the intrinsic features of the disease and the possibility of intercurrent clinical events, treatment side effects and comorbidities, which can cause sudden changes in the clinical pictures.

Considering these aspects, the model named "simultaneous care", which is deeply multidisciplinary, seems to describe the best approach to neuro-oncological patients. This approach not only ensures the "continuity of care" (adherence to treatment protocols—in terms of both dose intensity and the dosing interval) but also introduces the supportive care (control the side effects related to treatment and manage comorbidities related to malignancy) and palliative care (prevention and the relief from suffering) at the same time as anticancer therapies are administered (simultaneous care) [20].

9.5 Sensory-Motor Rehabilitation

The health benefits of regular physical exercise have been recognised for centuries, and structured exercise training is considered critical for primary and secondary disease prevention in multiple clinical settings. However, for neuro-oncological patients until recently, clinicians were either not aware of rehabilitation services or do not believe in the benefits of rehabilitation or just were uncomfortable providing such care for a progressive disease with poor prognosis. Only in the last decades has rehabilitation gained acceptance as a potential adjunct therapy for cancer patients.

Cancer rehabilitation attempts to maximise patients' ability to function, to promote their independence and to help them to adapt to their condition, improving their QoL, no matter how long or short the timescale. Rehabilitation is recommended throughout the course of the disease with different aims according to patient's needs; indeed, because of diverse clinical picture and varying levels of disability, an individualised approach is always warranted. In the early phase, the intervention aims to restore function [7], while in more advanced stages, rehabilitation is an important part of palliative care with the aim of preventing complications, controlling symptoms and maintaining patients' independence and QoL.

When planning the rehabilitative intervention, specificity of medical treatment, complication of surgery and side effects of irradiation and chemotherapy such as fatigue have to be taken into consideration; side effects of corticosteroids and anticonvulsants are also relevant, because their chronic use can be associated with myopathy, osteoporosis, behavioural changes and psychiatric disorders that can all influence the rehabilitation process [21]. Oncologic and other treatments may also impact the timing of physical therapy interventions, which should be performed in a phase of patient's peak performance [5].

To date, about a hundred studies have been performed investigating the effects of structured exercise training in cancer population. Although studies were considered with "low level" of evidence [19], papers that specifically addressed the effects of rehabilitation in neuro-oncological patients demonstrated that BT patients, after inpatient rehabilitation, achieve functional improvements comparable to stroke or traumatic brain injury patients, irrespective of the tumour type, location and concomitant tumour treatment [5–7]. Meta-analyses and systematic reviews reported that structured exercise training is a safe and well-tolerated therapeutic strategy associated with significant improvements in a broad range of cancer-related toxicities including physical, fatigue, exercise capacity and improved quality of life. As a result, a number of exercise guidelines for cancer patients have been published.

In brain cancer trials, "established" clinical outcomes are usually represented by progression-free survival or overall survival that considers tumour control and containment of treatment side effects. In rehabilitation, objective assessment of patient function and performance is generally preferred.

Performance status is widely used at baseline because of its prognostic value, but there is relatively little emphasis on functional status as an outcome, although changes in performance may indicate the effect of a rehabilitative intervention as well as the presence of clinical progression.

There are two commonly used outcome measures of overall rehabilitation functional outcomes: the Barthel Index, the simpler tool that focused on basic mobility function and personal activities of daily living, and the Functional Independence Measure (FIM®) that other than motor function and activities of daily living also includes cognition-communication. Although other tools can be used to measure multiple aspects of physical functioning in cancer patients, these tools are accepted in the literature as useful to describe overall patients' functioning.

In the neuro-oncological literature, the Karnofsky Performance Scale (KPS), Fig. 9.3, is the most widely used outcome measure that allows patients to be classified as to their functional impairment. The lower the Karnofsky score, the worse the survival for most serious illnesses. However, this scale presents important drawbacks, among which the most relevant concern is the fact that it was not specifically designed as an assessment for people with brain disease and therefore is oriented towards physical illness, rather than the effects of brain impairment (the concept of dependence, e.g. does not take account of the difficulties typical of people with cognitive impairment).

A further weakness of the KPS is that the lower levels of function are partly defined by dependence on medical support in hospital (an adaptation has been proposed that is appropriate for patients living at home). Given the limitations of the KPS as an outcome for brain tumour studies, at present there is a gap in the tools available for brain tumour studies, and there is a need for consensus over whether it is sensible to try to adapt the existing instrument, or whether it would be better to adopt another approach. The overarching aim is to achieve an international consensus on the core outcome set in neuro-oncology, also considering the patient-related counterpart.

Finally, in recent years, interest is growing in determining whether the benefits of exercise therapy may extend beyond symptom control to modulate cancer-specific outcomes (i.e. cancer progression and metastasis). Accordingly, over the past several years, research tried to shed light on the potential association between physical exercise, objective measures of exercise capacity/functional capacity and prognosis following a cancer diagnosis as well as the cellular and molecular mechanisms underlying these associations. Knowledge of the effects and underlying mechanisms will be critical to inform hypothesis-driven clinical trials and ensure the optimal safety and efficacy of exercise in cancer control.

Karnofsky performance status scale		
Able to carry on normal activity and to work; no special care needed	100	Normal no complaints; no evidence of disease
	90	Able to carry on normal activity; minor signs or symptoms of disease
	80	Normal activity with effort; some signs or symptoms of disease
Unable to work; able to live at home and care for most personal needs; varying amounts of assistance needed	70	Cares for self; unable to carry on normal activity or to do active work
	60	Requires occasional assistance but is able to care for most of his personal needs
	50	Requires considerable assistance and frequent medical care
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly	40	Disabled; requires special care and assistance
	30	Severely disabled; hospital admission is indicated although death not imminent
	20	Very sick; hospital admission necessary; active supportive treatment necessary
	10	Moribund; fatal processes progressing rapidly
	0	Dead

Fig. 9.3 Karnofsky Performance Status Scale

9.6 Neuropsychological Issues: Cognitive Rehabilitation and Psychological Support

9.6.1 Cognitive Rehabilitation

Cognitive deficits in neuro-oncological patients may be found in one or more cognitive domains, such as executive functioning, language and memory, with the prevalence ranging from 29% to 90% according to different tumour types; patients often report short-term memory and attention deficits as well as problems in word-finding and in carrying out complex tasks [22, 23]. In turn cognitive deficits can have major consequences on patients QoL, return to work or autonomy, as well as on patients' ability to make informed decisions related to their own treatment and care.

Factors affecting cognitive functioning can be related to the patient (e.g. age, education, psychological distress), the tumour (grade, location, biological features, etc.) and to the treatments (chemo-/radiotherapy, surgery). Mechanical effects of the tumour mass inducing ischaemic changes in the surrounding tissue, cell death by tumour-released excitotoxins and alterations in synaptic transmission can produce direct neuronal damages in the region of the tumour, as well as more widespread alteration of brain connectivity that harms cognitive functioning. *Chemobrain* or *chemofog* is the term used to describe cognitive side effects of chemotherapy that manifest as a decline in memory, concentration and executive functions; also, the early- and late-delayed radiotherapy effects on cognition have been widely described [22].

As focal and more evident neurological deficits may often cover cognitive impairments, a comprehensive and sensitive neuropsychological evaluation is necessary to detect possible deficits; conversely, standard screening tests aimed at cognitive decline are often useless because they lack sensitivity and domain-specific information. Cognitive status was found to be a stronger prognostic factor for survival than physical state, as assessed by the Karnofsky Performance Scale and reliable also as an index of tumour progression. A lot of studies also reported a negative prognostic value of cognitive impairment on recovery, while a significant positive correlation between mental status at admission and functional outcome after rehabilitation treatment was found in other studies [24].

As pharmacologic interventions have not proven effective yet in the treatment of cognitive deficits in patients with gliomas, cognitive rehabilitation could represent a therapeutic option aiming at relieving patients' cognitive deficits, improving the individual abilities to perform cognitive tasks, by retraining previously learned skills and/or teaching compensatory strategies, with the ultimate goal of fostering a positive adaptation of the patients to their environment.

Literature evidence in this field is still scarce, but preliminary evidence suggest that cognitive rehabilitation has a beneficial effect on cognitive performance and mental fatigue [24, 25]. Studies addressing the cognitive functioning of neuro-oncological patients by use of specific neuropsychological tools could prove to be very interesting, particularly in view of the evidence of effectiveness of neuropsychological rehabilitation reported in national and international guidelines on the management of stroke.

In the context of a multidisciplinary approach, cognitive rehabilitation can be combined with occupational therapy (OT) aimed at facilitating engagement in meaningful everyday activities and maintaining or improving patients' independence in performing the activities of daily living (ADL), through the use of a variety of techniques and tools (see Chap. 16 on AHP input for details).

Goals are defined in collaboration with the patients to identify the activities most important to their QoL. Usually training focuses on improving the patients' functional capacity, body, activity and participation level by adapting activities, regaining or developing activity abilities and/or rebuilding and developing patient skills for preserving functional independence and avoiding the necessity for care from others [26].

Even if OT has the potential to limit and reverse cancer-related disability, it still remains severely underused in BT patients. Barriers to a wider utilisation of OTs are represented by the poor awareness of OT by the health professionals, lack of knowledge of whom OT would benefit and the practical accessibility to the service.

As more cancer rehabilitation programmes are developed and the scope of OT becomes better understood, accessing an occupational therapist will become more standard practice. Occupational therapists treat each patient holistically and use creative solutions to improve the overall cognitive and functional capacity of patients, making the occupational therapist a critical member of the multidisciplinary team.

9.6.2 Psychological Support

Feelings of anxiety, depression and future uncertainty were shown to be highly prevalent among BT patients as psychological reactions to the disease and to the treatments. Patients with HGG report higher levels of panic, depression, anxiety and fear of death than patients affected by low-grade gliomas. Besides being a response to stress, psychiatric symptoms may also depend on tumour location, patient's premorbid psychiatric status and cognitive impairment. Due to the dramatic emotional sequelae of having a BT, it is important that patients are routinely screened for psychological distress to implement adequate support intervention to improve their psychological well-being.

Psycho-oncology as an integral part of oncology has become internationally recognised, though it has not always been implemented as standard care. The primary aim of psycho-oncological management is to retain and optimise the subjective QoL of cancer patients throughout the illness trajectory, providing existential support to facilitate adjustment to diagnosis, treatment and end-of-life issues. Literature evidences suggest that many people appreciate the opportunity to discuss existential fears and concerns early in the illness rather than support only being offered towards the end of life. This is particularly relevant considering that disease progression can greatly compromise people's cognitive and communication skills.

The effectiveness of psycho-oncological support (that ranges from psychoeducative measures to psychotherapeutic interventions) has been shown in various studies, both in group and individual therapies.

Professionally or peer-led support groups may provide patients with cancer with a sense of community, unconditional acceptance and information about the disease that they would not experience elsewhere. In addition, support groups have in different settings repeatedly been shown to increase the well-being of the patient. They may also facilitate the patient's relationship with family and friends by relieving the burden of care and providing a safe place for the expression of emotions [27].

9.7 Family Care

Several studies have documented the considerable burden and distress that caregivers may face as a result of providing care without being trained or prepared for this role, with substantial physical, social and psychological consequences [28].

Caring for BT people in fact may be particularly challenging because of the rapid progression of the disease; the presence of cognitive impairment and behavioural changes; the fast, physical deterioration; the changes in family life that require the caregivers to take on new roles and responsibilities; as well as the uncertainty of the future. In a short time, a high level of assistance with personal daily living tasks, problem-solving and decision-making is often needed. In turn, caregivers' psychological and behavioural responses to caregiving may impact on their own emotional and physical health and may also influence the quality of care delivered to the patient at home as well as the decision to institutionalise patients.

Intervention research suggests that educational programmes and cognitive-behavioural therapy may relieve neuro-oncology caregiver distress and that identifying and addressing concerns early may lead to better carer health outcomes. Recommendations from literature include having educational programmes for caregivers to prepare them for changes in their loved one and to increase understanding of treatment processes, teaching caregivers stress reduction techniques and coping strategies, involving caregivers more in communication and having family consultations in the crisis phase. In spite of this, the evaluation of family caregivers' support needs is often neglected while focusing primarily on the patient, resulting in informal and undocumented needs assessment. As evidenced in the literature, the most prevalent caregiver needs soon after diagnosis usually regard "getting information about the illness and its evolution" and "dealing with fears and worries", while at follow-up visits the needs usually shift on "getting a break from caring", "practical help in the home" and "equipment to help care" as well as "managing patient's symptoms" [28].

Professional support in assessing and meeting the unique support and palliative care needs of family caregivers of BT persons is imperative to enable them to continue their caregiving activities, easing their burden and maintaining the best possible level of patients' well-being.

9.8 QoL and Palliative Rehabilitation

Despite multimodal treatment, the vast majority of BT patients cannot be cured and have a poor prognosis. Therefore, the benefits of therapies, in terms of prolonged survival or delay of progression, have to be carefully weighed against the side effects of the treatments, which may adversely influence the patient's functioning and well-being during his/her remaining life span. For these patients the attainment of an acceptable quality of life is at least as important as the duration of survival.

Health-related QoL (HRQOL) is a multidimensional concept that includes physical, emotional, cognitive, social and spiritual aspects that are believed to be influenced by a person's experience, beliefs, expectations and perceptions. Although some concerns regarding HRQOL appear to be universal (e.g., emotional distress and/or impaired functional status), many others are uniquely determined and depend on the presence of factors that may initially appear unrelated to the disease process.

As QoL reflects the patient's subjective evaluation of important and personal aspects of his/her well-being, HRQOL measures should be patient-reported, even if proxy-reported are still used when patient evaluation is no longer feasible.

In recent decades, with the debate on whether the survival endpoint alone can provide sufficient evidence of the superiority of one treatment modality over another, HRQOL has become an increasingly important endpoint in cancer studies, next to outcome measures such as overall survival, progression-free survival and time to tumour progression, and the American Society of Clinical Oncology has suggested that QoL measurements should be primary endpoint in any phase III study.

Measuring a complex aspect of the person, such as QoL, is by no means easy and a lot of instruments were developed over the course of years.

One frequently used HRQOL tool used for cancer patients is the European Organisation for Research and Treatment of Cancer (EORTC) QLQ-C30. This questionnaire contains 30 items organised into five functional scales: three symptom scales, one global health and quality of life scale and several single symptom items. The EORTC QLQ-C30 is often used in conjunction with the brain tumour-specific questionnaire, the EORTC QLQ-BN20. This questionnaire, developed for and validated by BT patients, consists of 20 items subdivided into four multi-item scales on future uncertainty, motor dysfunction, communication deficits and visual disorders.

Although HRQOL is important in all stages of the disease, it is of utmost importance in the end-of-life phase, when the main goals of palliative care are to offer adequate symptom control, to maintain the QoL of the patients and their caregivers through the relief of suffering, to provide psychological support to spiritual needs of patients and families and to facilitate a calm and dignified way of dying, without inappropriate prolongation of life.

In end-of-life phase, medical concerns are often in regard to non-treatment decisions (withholding or withdrawing) around therapies given for the alleviation of symptoms. However, often in advanced stages of the disease, patients manifest cognitive deficits, confusion and disorders of consciousness that may reduce their competence and ability to participate in such critical decisions, leaving the whole responsibility on caregivers.

Hence, as patients' participation in end-of-life decision-making is only possible at a relatively early stage in the disease course, advance care planning should be considered to reach a consensus about possible end-of-life decisions, in order to obtain a consensus, respecting both patients and caregivers' values and warding patients' autonomy [29].

9.9 Nurses' Role in Rehabilitation

Until recently, the figure of nurses in rehabilitation has often been considered marginal as if their only role was to "prepare" patients for rehabilitation and much of nurses' care remained invisible, receiving relatively scant attention in the literature.

Actually, most of nurses' activities represent essential rehabilitative skills, used by rehabilitation nurses every day such as easing pain, mobilising, healing pressure areas or caring for wounds, providing adequate nutrition and hydration, administering medications and caring for sleep, rest and stimulation. Although the ultimate goal of rehabilitation is to enable patients to live as independently as possible, rehabilitation nurses may also be required to assist patients with everyday tasks as well, such as bathing and dressing, personal hygiene and continence.

As suffering from a disability or having a loved one who suffers from a disability can be very confusing and frustrating at times, rehabilitation nurses are also asked to provide patients and caregivers with education and emotional support in addition to their other roles. Of particular significance is the creation of a supportive environment for rehabilitation to occur. Unless such needs are fully met and built into an educational rehabilitation programme, all other activities are ineffective.

In addition to their clinical role, rehabilitation nurses also have an important administrative function, effectively acting as case managers, especially in acute care and acute rehabilitation settings. In this role, nurses must advocate for patients and families, representing their concerns regarding care both within and outside the clinical setting; moreover, nurses may provide a link between patients and families and the hospital. Patients and relatives often describe the role of the nurse specialists as one of active companionship throughout the disease, appreciating in particular qualities as availability, proactive and flexible support, professionalism and personal tone. The close contact with families allows nurses to identify caregivers whom are at risk of negative emotional and physical reactions to providing care and to plan appropriate and effective interventions to meet their needs. In fact, nurses are an essential resource to caregivers to assist with bringing out care demands as well as identifying resources that can decrease distress of meeting care demands. Nurses are often responsible for both teaching family and caregivers tasks of care and disease and symptom management, as well as being responsible for identifying factors that may place caregivers at risk for negative consequences and intervening with the caregiver as necessary. Other topics frequently addressed by nurses include reinforcing information already given or providing additional information about treatment and side effects, changing of appointments, symptom advice and test results. The case manager must review each patient individually to establish what treatments and services are appropriate. This role is bound to become increasingly important in the context of the ever-increasing need to achieve better management of resources and shorter hospitalisations.

After discharge the district or community nurse has the potential to play a central part in community rehabilitation provision, by making assessments, referring on to other members of the multi-professional team, advocating for and liaising with other services, helping people to adapt, teaching and motivating patients and carers, supporting and involving families and providing technical care. A number of challenges to community-based nursing roles were apparent, including feelings of exclusion, lack of recognition, a lack of time for rehabilitation and paucity of referrals for rehabilitation by clinicians. Greater clarity and recognition is needed of the community-based nursing contribution to rehabilitation, and there is a need to ensure that community nursing assessments contribute to patients' rehabilitation goals and the promotion of independent living.

Specifically, in the field of neuro-oncology, the introduction of nurse specialist was strongly advocated; nurses who are interested in neuro-oncological rehabilitation are concerned with changes and functional abilities, rather than the disease process, and with how to improve the remaining time, rather than with how many months an individual has left to live.

The complexity of knowledge and skills required to provide such comprehensive care to neuro-oncological patients illustrates the need for increasing specialisation within the health professions. Although nursing is purportedly about meeting the needs of all, the development of an understanding of patients with disabilities is one area that is generally not given specific attention in undergraduate nursing curricula. Only a third of nurses felt, with hindsight, that their preregistration education had provided them with adequate skills and knowledge for their role in rehabilitation; furthermore, nurses have expressed the need to have access to more education and training focused on rehabilitation per se and associated clinical skills, in order to strengthen and raise the profile of their professional role. In this regard, recent studies supported this view [30], and surely *The Specialty Practice of Rehabilitation Nursing: A Core Curriculum, 7th Edition*, published by the Association of Rehabilitation Nurses (2015), represents a key text in this area.

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