

The Rehabilitation Setting of Terminal Cancer Patients: Listening, Communication, and Trust

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Abstract

Given the particular nature of the oncological context, the relationship between the physical therapist and terminally ill patients may, at times, be very demanding from an ethical point of view. The approach taken to rehabilitation should be extremely flexible and adaptable to the rapid changes which the evolution of the disease imposes on the patient: moreover, through a multidisciplinary approach and with the co-operation of a team of other healthcare professionals, the physiotherapist can adequately support the patient and his family. Cancer patients in the advanced stages of the disease must confront the progressive nature of the condition and the consequent deterioration of physiological functions. It is because of these changes that the physical therapist is a crucial part of the palliative care process; however this role is not without its issues, for example, the different operating models and the effectiveness of each professional choice. This paper represents an attempt to analyze, especially from a bioethical point of view, the activities of the physiotherapist in the particular context of palliative care, a context which is made difficult by the nature of terminal diseases, and by the need for effective listening, communication, and trust when interacting with patients who are reaching the end of their life.

Keywords: Rehabilitation Setting; Terminal Cancer; Listening; Communication; Trust

Introduction

Thanks to scientific and medical advances in recent years, the idea that cancer is synonymous with death is no longer valid; in fact, a full and proper consideration of the needs of cancer patients, which differ depending on the stage of the disease and which determine the type of required rehabilitation for disease prevention, recovery and support, has become of utmost importance [1,2]. The meaning of rehabilitation at some stages of an oncological disease is easy to understand, but it may seem almost a contradiction to talk about rehabilitation efforts at the terminal stages, when the expectation is that the patient is approaching death. Unfortunately, it still is a widespread belief that rehabilitation and palliative care are two opposite terms, especially when economic resources are limited and healthcare resources should be evenly distributed. In this perspective, article 8 of the Charter of Paris, prepared and endorsed at the World Summit against cancer for the new Millennium in 2000, declares that *“to improve the quality of life for cancer patients is a goal of primary importance in the fight against cancer. Both the physical and the emotional weight of this disease can have a strong impact, and are also often a consequence of side effects of the treatment. Because clinical outcomes can be influenced by general condition of well-being, both physical and mental care must be given to maintain the quality of life; both physical and social care should be a humanitarian and medical priority”* [3]. For terminally ill patients, even if physical functions are no longer reliable in the long term, it is nevertheless important to take care of them, in order to improve their quality of life and to satisfy their need for autonomy and self-determination [4]. Regarding the definition of health, which has evolved over the years, we believe that it is interesting to consider the Italian National Committee of Bioethics, in the opinion piece *“Bioethics and Rehabilitation”*, published in 2006 [5]. In this document health is defined as a “balance”, implying that the alteration of this balance may bring about disease, which does not assume the characteristics of a simple accident, but becomes an opportunity to find a new balance through a process of growth, awareness, and responsibility. Following this point of view, a person could be defined as “healthy” when he/she is able to live a free and conscious life, valuing all the energies in his/

her possession; on the contrary, a person should be considered “sick” if he/she is incapable, or not sufficiently capable, of managing his/her life in a conscious and free manner, nor of enhancing all of his/her skills and energies. Therefore, it seems clear that “health” should not be considered as a static and impersonal concept.

Similar considerations could be applied to the oncological setting: cancer is a fact of human life, experienced by individuals as an existential threat, but also as an existential possibility, like a new experience where the patient has the opportunity to revisit his/her habits, lifestyle, values, and projects. In this context palliative care assumes paramount importance: developed with a scientific medical connotation about 40 years ago in England, today it represents a global and multidisciplinary care for patients suffering from a disease that does not respond to specific treatments [6]. The ultimate meaning of palliative care is to improve as much as possible the patient’s quality of life, finding a balance between the emptiness of therapeutic abandonment or euthanasia on one side, and life-prolonging measures on the other. At the basis of the development of palliative care there is a new cultural approach, in which death is no longer considered as the opposite of fighting, but as the last act of life. The end of life is accepted as a natural and inevitable fact for every human being; hence the priority should be the patient considered in its entirety. Full and serene awareness of death involves a greater attention to the quality of life and to the suffering of those who are about to die [7,8].

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Oncological Rehabilitation: An Ethical Perspective

Cancer rehabilitation aims at helping the person suffering from cancer to obtain the maximum recovery of physical, psychological, and social wellbeing within the limits imposed by the disease and its treatment, trying to satisfy as far as possible the needs of the patient [4,9].

In theory, the rehabilitation of cancer patients does not differ much from rehabilitation for other diseases but in practice, when dealing with an oncological patient, a number of other factors are involved, making their habilitation intervention in this setting very particular. The muscle weakness, the enticement, the lack of planning and of appropriate stimuli to the individual case may cause loss of autonomy, thus contributing to the general sense of inadequacy, depression, irretrievable disability, and addiction. It is in these aspects that the oncology rehabilitation shows its peculiar nature, with its ability to remain flexible, to change moment by moment based on the extreme variability of the clinical picture, to define goals attainable by anyone with the patient and his family, and to avoid confusion and frustration. In this context, while taking care of the sick, you can't forget the family; family members need to be supported and guided in order to help the patient throughout the course of the disease [9]. For the family, the incurable forms of the disease constitute an existential strain: indeed, the tragedy of suffering the loss of a loved one adds problems of other kinds (relational, emotional, economic, and organizational). Similarly to what happens to the sick person, the family will face feelings of denial, anger, depression, and illness related to the upcoming death. The family can decisively contribute to the attitude of the ill person, and therefore the family must be regarded as an integral part of the care program.

The Role of Physiotherapist

In the oncological setting the physiotherapist should provide a comprehensive therapeutic intervention aimed at improving the quality of life for the individual and his/her family. The complexity of palliative care responds to this requirement. Palliative care has been defined by the World Health Organization as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual" [10,11].

It often happens that the rehabilitative intervention is requested too late or even not at all due to a fatalistic attitude and a general pessimism of the attending teams; although in many cases it is difficult to realistically assess the life expectancy of the cancer patient. These interventions, if well integrated and coordinated, can prolong life, prevent the establishment of secondary damages, reduce pain, and improve mobility, transfers, and "self-care", reducing the sense of isolation that this disease frequently brings about, and allowing the best possible quality of life. To achieve the best results, maximum integration and respect of the competencies of the different specialists is required. Therefore, unlike what frequently happens in practice, the rehabilitative intervention should be started early, be continued, and include interdisciplinary actions [12,13].

From the standpoint of rehabilitation, the cancer patient presents unique challenges that can be divided into two basic categories:

1) Rehabilitation issues, common to all types of cancers, which occur for iatrogenic causes and/or as the disease progresses;

2) Rehabilitation issues, organ-specific problems that are related to the primary tumor localization and its possible surgical resection.

The disabilities of terminal cancer patients, which result from multiple factors, vary by the type of the disease and by the patient's responses to treatment. In a clinical picture like that of the terminal cancer patient, there are often consequences due to constraint, musculoskeletal complications, and neurological issues due to the progression of the pathology, anticancer treatments, results of the surgery, etc. It must be kept in mind that this type of patient has for a long time undergone major aggressive therapies, many of which exposes him/her to the risk of increased toxicity due to the treatments themselves. The symptoms which are reported most frequently are pain, weakness, fatigue and dyspnea, hypokinetic syndrome, anorexia, nausea, vomiting, delirium, depression and anxiety, and difficulty sleeping, which add to other characteristic symptoms of the disease as physical limitations and neurological complications. In the terminal stage of the disease, patients are often bedridden or in wheel chairs; they lose important autonomy and must be assisted in the needs of everyday life. Patients will suffer from progressive weight loss with consequent asthenia, and will suffer psychologically because of their dependence on caregivers, their isolation, and the prospect of uncontrolled pain, because of the negative impact that these factors have on functional performance [4,14]. In fact, many patients fear these elements (pain, isolation, and loss of motor function) rather than death itself. Cancer patients want to stay independent in self-care, in their jobs, and in their activities. When they perceive that they are progressively less independent in carrying out such activities, they begin to feel that they are a burden to their families and this is experienced as a stress, causing a significant deterioration of the quality of life. Rehabilitation can make a positive contribution both to the relief of symptoms (pain, dyspnea, etc.) and to maintaining, and sometimes recovering, some lost functions. Adaptation strategies which allow the person to find the best way, for example, to walk or eat alone, will increase their level of autonomy [15].

Listening to the Patient and the Family

The first and fundamental step is to develop with the terminal patient a "positive relationship", which we could define as being based on three key points: listening to the patients, good communication, and trust between health-care professionals and patients.

"Listening" means understanding what the problems, needs, and desires of the patient are, but the immediate and traditional meaning of this first element should be expanded. The therapist has the opportunity to "hear" the patient through direct physical contact with a body that transmits its sorrow and its fragility. The stage, or better, the approach of listening, allows the therapist to have a close observation of the patient's reactivity and gesture, interpreting those movements through experience.

The patient needs instant realistic answers, and the therapist is called upon to respect and accommodate these needs. For this reason, it is important for the negotiation and management of rehabilitative objectives to be based on the following assumptions:

- Objectives should offer a dynamic (and not static) vision of life;
- Goals can be affected, regardless of the state of the disease and the clinical situation, also by psycho-social diversities between patients and families;
- The rehabilitative intervention may play a key role in identifying

and trying to achieve goals that go beyond the rehabilitation aspect in the strict sense;

- Hope, in palliative care, doesn't rely on false optimism or benevolent reassurance, but on the conviction that better times can still occur despite the disease.

Communicating with the Patient

The therapist, in addition to traditional communication sometimes facilitated by moments of intimacy and a two-way relationship with the patient, receives and transmits important non-verbal communication signals, thanks to his specific therapeutic activities. In fact, the physical therapist is the figure which, together with the professional nurse or the social health operator, has the power to "touch" the patient. By taking care of the body, the therapist has greater possibilities of establishing a positive relationship with the patient.

Probably the greatest challenge in the rehabilitation of cancer patients in advanced stages is the definition of appropriate objectives, which must be shared with the patient. The many differences in the pathological, psychological, and environmental factors makes it difficult, if not impossible, to formulate final guidelines regarding rehabilitation techniques for terminal cancer patients. The multidisciplinary approach allows the objectives, the cure, and the centrality of the person to be adapted to the particular and not standardized context of each individual. Establishing a relationship with patients in the terminal stages is challenging, tiring, and sometimes difficult. In this context, the empathy of the operator implies a deep involvement, both as a professional and as a person.

Trust in the Relationship

The fundamental element in the patient-therapist relationship is trust. The trust relationship must be set starting with the clear definition of the rehabilitation project and of realistically achievable goals [16]. In this context, the therapist should try to rescale the pessimism concerning the evolution of the situation, thus enhancing positive results, even if modest. Every success, even if minor, contributes to improving the quality of life of the patient: the incremental increase, or sometimes the simple maintenance of certain aspects of autonomy, can have great value for those who live. It should be noted, however, that in a trust relationship the therapist should leave space for the expression of doubts, perplexities or loss of motivation of the patient. For this reason, it often happens that, in the relationship between the therapist and the terminal patient, the subject of a negotiation of the objectives will arise.

Within the terminal stage, time becomes a precious element. It is for this reason that therapists should establish short-term rehabilitative objectives, such as maximizing the capabilities of the patient and improving his/her quality of life, securing transfers to and from the wheelchair or allowing the patient's environmental control, always based on the prognosis of exercise tolerance, dyspnea, fatigue, etc. It therefore becomes important to highlight how the patient remains a living person until his/her death, and therefore it is fundamental to maintain the respect for the suffering human being, the attention to detail regarding the patient's life. The last phase of life must be rendered less distressing, and a decent quality of life must be preserved.

Working as a team

The relationship with the dying is extremely demanding from all perspectives. Therefore, one operator providing care alone, even if he/she is well trained and well-motivated, is not always adequate

to respond to the care needs of the patient, and may also be unable to withstand the context in which care is provided. A team therefore seems like the correct approach in the complex context of palliative care, but, besides aside from this aspect, this configuration enables the individual operator to demonstrate to the full his/her professionalism. Expanding the team approach to a more general context, the correct approach seems to be the civil society which can and must give to the patient and his/her family.

The team is a small community of people, which has a legacy of experience and technical resources, operational and emotional. It represents a way of working that has proven to be effective, even with its limits. The relationship with the dying is a positive experience on a personal and professional level, but it requires a technically well-defined and structured intervention [9]. A good relationship with the patient requires a real collaboration between members of the team: they strengthen each other in dealing with the psycho-emotional stress, and they support each other when a situation emotionally involves one operator with consequent anger or depression. A good team can guarantee to the terminally ill and his family adequate assistance that sustains the patient in all his physical, spiritual, psychological, and social needs. A successful team achieves better approaches to listening, communication, and above all, trust.

Conclusion

Cancer rehabilitation is a reality that is increasingly present and required, and it is developing along with the dissemination of a culture of action. This culture places the sufferer at the center of attention, with his/her problems, needs, and aspirations; the patient is considered first and foremost a person, even when confronting the last acts of his/her life. The aim of rehabilitation is to achieve the best quality of life for the patient at that time, given the limitations that may arise from the situation. This can translate into simple acts which can have an important effect on the person: from contributing to the reduction of pain to supporting the remaining autonomy. Of fundamental importance is the identification of achievable and flexible objectives, which must be shared with the patient to avoid misunderstandings and frustrations on both sides and to reinforce the therapeutic alliance.

With this paper we wanted to point out that the key to success for the development of a positive rehabilitation intervention, is linked to the integration of the physiotherapist with the patient in the first place, and also with his family and with the rest of the palliative care team. It is, in fact, thanks to a multidimensional assessment of the needs of the patient that the physiotherapist can propose the most appropriate actions with respect to each need. The team also represents a source support for the therapist himself, when faced with a reality in which the needs of the patient are complex and the relationship with the dying person is emotionally challenging.

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