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Palliative Care in Polish Patients with Multiple Sclerosis

Jozef A. Opara[1,3*], **Waldemar Brola**[2] **and Jaroslaw Szczygiel**[3]

[1]*Department of Physical Education, Jerzy Kukuczka Academy of Physical Education, Katowice, Poland*

[2]*Department of Neurology, Specialist Hospital in Końskie, Poland*

[3]*Repty Rehab Centre in Tarnowskie Góry, Poland*

[*]**Corresponding author:** Jozef A. Opara, MD, PhD, Department of Physical Education, Jerzy Kukuczka Academy of Physical Education in Katowice, Poland, Tel: +48-32-2075301; Fax: 32-2511097; E-mail: jozefopara@wp.pl

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Abstract

Multiple sclerosis is a progressive disease of the central nervous system with unknown aetiology. It most frequently affects young adults and inevitably leads to disability. Despite significantly progressing development of immunomodulatory treatment, access to which in Poland is limited, the number of patients requiring continuous care and being unable to live independently is constantly growing. The specificity of MS symptoms results from damage of almost all functional systems of the nervous system. The physical, mental, cognitive and psychosocial consequences associated with the symptoms significantly decrease the patients' quality of life. Patients with advanced stage of multiple sclerosis actually qualify for palliative care, which in Poland is reserved mainly for oncological patients and rarely for other groups of patients. The Polish legal system does not provide guaranteed benefits for people with MS requiring palliative and hospice care. Therefore, it is necessary to take action aimed at supporting the most disabled patients who are deprived of the modifying treatment and are only left to symptomatic treatment.

Keywords: Multiple sclerosis; Health-related quality of life; Palliative care; Poland

Introduction

Multiple sclerosis is one of the most prevalent causes of neurological disability in young and middle-aged people. The course of this disease is diverse and hardly predictable. It ranges from mild to quickly progressing form leading to severe disablement, with a relatively fast deterioration of neurological functions and imposed necessity to change the style of life [1]. The course of MS depends on many factors and can be affected mainly by the applied immunomodulatory treatment (i.e. interferon, glatiramer acetate, natalizumab, fingolimod). Unfortunately, the efficacy of the therapy is limited, and in Poland not all patients are entitled to use it. Moreover, despite treatment the disease still progresses, increasing the disability which strongly affects the patient's quality of life as regards the physical, mental, cognitive and psychosocial sphere [2-4]. Therefore, it is crucial to provide support to the patients with the most severe disability who are confined to wheelchair or bedridden.

Multiple sclerosis in Poland

The number of MS patients around the world exceeds 2.3 million and approximately 600,000 of them live in Europe [5]. It is estimated that in Poland there are 40,000-50,000 such patients, with 1,100-1,700 new cases diagnosed every year. The prevalence of MS in Poland is estimated at 37-91 cases per 100,000 citizens [6]. As reported in "MS Barometer 2013", published by the European Multiple Sclerosis Platform (EMSP), in Poland immunomodulatory treatment is applied in 11% of cases [7]. The above-mentioned data indicates that the vast majority of patients does not receive treatment modifying the course of the disease. Assuming that in half of them MS has not lasted long enough and/or its course is mild, there is still over 20,000 people at advanced stages of the disease, requiring palliative care and left only to symptomatic treatment. "MS Barometer 2013" also reports that in the ranking of the quality of life in MS patients, Poland takes the last place out of all 23 countries [7]. Hindered access to refunded medical help and medications delaying the progress of the disease and the disability makes MS patients in Poland live by approximately 17 years shorter than their peers [7]. In most countries of the EU, multiple sclerosis does not significantly affect the patients' life span and patients frequently remain professionally active until retirement.

The World Health Organisation defined palliative care (PC) as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" [8]. The aim of palliative care is to aspire to achieve the highest quality of life for the patient and his/her family members [8]. However, palliative care in Poland is mainly reserved to oncological patients [9]. Epidemiological data indicates that 90–95% of palliative care services is offered to oncological patients. However, it is estimated that in the future the share of patients with non-oncological diseases can grow up to 40% [4,9].

Palliative care in multiple sclerosis

Multiple sclerosis is not a fatal disease but it leads to progressing disability and complications which can be life-threatening. These include: chronic renal failure associated with urinary incontinence, bedsores (being a consequence of disability), aspiration pneumonia, suicides, and depression (both as a symptom of the disease itself and as a result of the progressing disability). MS patients commit suicide seven times more often than the general population [10-12]. The progression of disability in most patients leads to permanent disablement and inability do live independently.

The course of MS mainly depends on the patient's age at onset and the type of the disease - prognosis is worse for patients with primary-progressive MS. According to Deggenhardt et al., in the relapsing-remitting (RRMS) and primary-progressive types of MS (PPMS) the negative prognostic factors include: occurrence of progression, higher number of bouts, greater disability within the first 5 years, shorter interval before the second bout and involvement of a larger number of systems [13]. Other negative factors include: shorter time to progression in the primary-progressive type and more quickly progressing disability during the first two years and five years in the primary progressing type [13]. Weinshenker et al. observed that up to 50% of patients will require devices helping them to walk within 15 years from the onset of MS [14]. In one of their last reports Tutuncu et al. published the results of a study of two cohorts of patients: with relapsing-remitting MS and with progressive clinical course (primary or secondary) [15]. Progression occurred before the patient's age of 75 years in 99% of patients with diagnosed progressive course of the disease, while in 38% of patients with RRMS progression did not develop before the age of 75 years. On both cohorts, only 2% of patients reached EDSS=6 (Expanded Disability Status Scale by Kurtzke) before progression. Thus the conclusion that the RRMS form of MS must not necessarily transform into a progressive one. The beginning of progression depends on the patient's age rather than the course of the disease before progression [15]. The above-mentioned reports indicate that palliative care in MS patients should be provided in respect of symptomatic treatment, psychological support and rehabilitation.

During the last several years there has been an ongoing international discussion concerning the need for inclusion of patients with the most severe types of MS into the program of palliative care [2-4]. The results of studies conducted so far indicate that such patients do not receive appropriate support from their attending physicians, who they usually cannot talk to about the prognosis and possible scenarios of the advanced course of their disease [2-4]. Also, physicians taking care of the patients not always have sufficient knowledge on the key problems of these patients and their unsatisfied needs.

Strupp et al. stated that patients severely affected by MS have a large range of unmet needs. Although initially counter-intuitive, specialized palliative care may be beneficial for these patients and their relatives. First randomized phase II trial has already demonstrated significant benefits for patients and their caregivers when PC was included in their care. However, there are barriers: neurologists not convinced about PC, or PC not taking on MS patients. Studies have shown that misunderstandings and lack of information among healthcare professionals about the roles and services of PC for MS are still prevalent [16].

Since MS patients still do not have appropriate access to palliative care, the British Association for Multiple Sclerosis carried out a study which showed that providing additional and supplementary services in palliative care significantly improved the quality of life of these patients [4]. Based on a 3-year research program, models of palliative care were worked out [4]. It has been shown that services included in the palliative care, ideally offered by experts in neurology, rehabilitation and psychology should involve treatment of symptoms, provide access to advanced medical care and rehabilitation, as well as give psychological support [4]. The study also provided us with important tips on how to develop the structures for palliative care: first of all by allowing for cooperation of new organisations with the old ones and sharing the knowledge about palliative care in patients with oncological diseases to that it is continuously popularized and improved [4].

The concept of palliative care for MS patients was included in the Code of Good Practices, which was formulated by the European Multiple Sclerosis Platform [7]. According to this Code, all patients with multiple sclerosis should have access to palliative care, and if needed, also to specialist services in palliative medicine [2-4,7]. As early as in 2003, the European Parliament (EP) issued a resolution forbidding discrimination of MS patients, pointing out that this disease is a social problem. Since most MS patients are at the working age, the consequences of the disease (especially the once of no access to appropriate medical and social care) affect not only the patients themselves, but also the entire society [7]. In accordance with the implemented resolution, the "European Code of Good Practice in MS" was worked out. According to this Code, all patients with multiple sclerosis should have access not only to the immunomodulatory and immunosuppressive treatment but also the symptomatic one, rehabilitation, palliative care and, if needed, specialist services of palliative care [2-5,7]. The Code was accepted by the EP and became the basis for providing appropriate quality of life to patients with MS. These activities are continued by the European Multiple Sclerosis Platform (EMSP) [7]. The recommendations of the EP and EMSP are respected only in several countries of the Western Europe, where palliative care for MS patients is a common practice.

In Poland the issues associated with palliative care are regulated by the Minister of Health Regulation of 29 August 2009, on Palliative and Hospice Guaranteed Services [17]. Unfortunately, the regulation did not pertain to patients with multiple sclerosis. In Poland PC is a specialist health service, financed from the public funds. Additional, minor support is provided by local governments and non-governmental organizations (associations and foundations). The National Health Fund finances services in palliative care offered for stationary (hospital departments of palliative medicine and stationary hospices), ambulatory (clinics of palliative medicine) and in-home (in-home hospices) conditions [9]. Patients with multiple sclerosis use these services in a very limited percentage only.

Indications for Palliative Care

In Poland palliative medicine as a separate specialty has been developing since 1999 and the palliative and hospice care mainly includes patients with advanced neoplasms who cannot receive causal treatment [9]. With years, more and more is being said about the need to extend palliative treatment to other groups of chronically and terminally ill patients [2-4]. One of these diseases is multiple sclerosis. The commonly observed symptoms which significantly limit the patient's fitness and contribute to his or her considerable discomfort were by Ben-Zacharia divided into three categories [2]. Symptoms of the first degree include: fatigue and exhaustion, spasticity, disturbed vision, sphincters dysfunction, sexual disturbances, problems with speaking and swallowing. Symptoms of the second degree, including: urinary bladder infections, skin damage, fractures and dislocations, hypersomnia, recurrent pneumonia and poor everyday activity. Symptoms of the third degree include: reactive depressions and psychological problems, social isolation, financial problems, divorces and problems associated with parenthood.

Progression of the disease leads to decrease in physical and cognitive abilities, emotional disturbances and disturbance of social functioning. In recent years there have been many studies carried out which showed that the quality of patients' life is affected not only by the physical disability but also the psychological and psychosocial factors [18-22].

Symptomatic treatment and rehabilitation constitute a very important element of palliative care in patients with multiple sclerosis. The main focus of neurorehabilitation management is not to restore the motor functions or compensate them, but to take care of the patient's condition, maintain his/her body's efficiency and prevent symptoms such as pain, bedsores, sphincters and mood disturbances in the best possible way.

Qualification for palliative treatment, including initiation of rehabilitation and palliative care, is a difficult decision, which should be made by a specialist team and based on clear criteria. It should not be treated as a verdict closing one's door to management aimed at improving the quality of life in terminal patients. In all cases it should be the patient's condition and the general qualification criteria that should be taken into consideration, though the criteria still remain quite controversial and are the subject of many discussions. The process of qualification should consider the neurological deficit, presence of life-threatening complications (urinary and respiratory infections, bedsores, thromboembolic symptoms) and the capabilities for the family to take care of the patient at home.

The needs in respect of palliative care are commonly assessed with use of the Palliative care Outcome Scale (POS) published in 1999 by Hearn and Higginson [23], as well as the Palliative Performance Scale (PPS) presented in 1996 by Anderson et al. [24]. POS consists of two identical questionnaires, filled in independently by the medical staff and the patient. The questions pertain to 10 domains: pain, other symptoms, patient's anxiety, caregivers' anxiety, information, support, life value, self-confidence, lost time and personal issues [23]. PPS is a simple and useful tool for qualification of patients requiring palliative care and allowing us to specify life expectancy. It is applied in various areas of medicine, including neurology. The cut-off point for qualification of a patient for palliative care is ≤40% [24,25].

Perspectives for the development of palliative care in Poland

At its advanced phase, multiple sclerosis, regardless of its type, usually leads to severe disability. Most patients are isolated, deprived of contact with people around and left to the care provided by their caregivers. Palliative care in these patients should focus on alleviation of the most common symptoms (spasticity, pain, fatigue or depression) and prevention of life-threatening complications. Also, it is important to provide conditions allowing the patient to preserve their independence for as long as possible and to offer psychological and spiritual support to the patient and his/her caregivers [26,27]. In Poland there is no system and there are no well-established methods for taking care of patients with severe disability caused by MS. In most cases patients stay at home, under care of their relatives, or go to health care centres or residential medical care facilities [28]. There, they are devoid of professional medical and psychological care of any kind. It seems that a home hospice is a good solution, which is a recommended and preferred form of palliative care [29]. The patients stay at home but are taken care of by qualified interdisciplinary team members, who visit him/her if needed. The patient can also use the medical equipment rented from a hospice, have follow-up examination conducted and be treated in case of aggravation of symptoms. In case of occurrence of symptoms difficult to manage at home or a need to conduct necessary procedures in in-hospital conditions, the patient should have immediate access to a department of palliative care or a stationary hospice [30]. A stationary hospice should also relieve the families of patients staying at in-home hospices by taking the patient over from time to time for 7-14 days. Solari et al. started on January 2015 RCT with a nested qualitative study designed to test the effectiveness of a HPA on people with severe MS and their caregivers. This trial will primarily assess the effect of the HPA on patient Health-Related Quality of Life (HRQOL) and symptoms; secondarily it will assess patient functional status and mood; carer HRQOL, mood and caregiving burden; costs, incorporation with standard care, unplanned hospital admissions, referrals to hospice, and deaths over the six-month period [29].

However, lack of financing by the NFZ (National Health Fund) of care to Polish MS patients makes it impossible to accomplish these aims. If hospitalization is needed patients are admitted to hospital departments of neurology or internal diseases.

Therefore, there is urgent need for creation of a Polish model of palliative care, based on experience from other countries [2-4]. In order to identify the rules of providing palliative care in patients with advanced MS it is necessary to establish a working group comprising neurologists, physiotherapists, psychologists, palliative medicine consultants as well as representatives of nurses and patient associations. Another step should be aimed at including multiple sclerosis on the ministerial list of guaranteed services in palliative and hospice care and is financed by the National Health Fund. Polish palliative medicine, which is still at its nascent stage of development, has many challenges ahead of it, which require implementation in the nearest future:

Evaluation of the number of patients with multiple sclerosis requiring palliative care and identification of the criteria for qualification of this kind of care.

Evaluation of the possibilities of financing and organizing in-home or hospice care.

Identification of the expectations of patients and their families as regards palliative care with assessment of their psychological needs at the advanced stage of MS.

Identification of team members for in-home and hospice care, necessary for providing a full scope of care (a qualified multidisciplinary team with extensive medical and non-medical experience).

Assessment of the efficacy of implemented actions, especially during motor rehabilitation and psychological support.

Assessment of the effect of palliative care on the quality of life of patients in Poland and their families.

It should be borne in mind that MS affects people at a relatively young age and it accompanies them at all stages of their individual development, family and social life. Keeping this in mind, we should focus on providing the patients with a chance to live their life to the fullest.

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