



## **The Role of Palliative Management in Multiple Sclerosis: A Narrative Review**

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**Abstract**

**Objective:** *This study aimed at determining the suitability of palliative treatment for multiple sclerosis patients.*

**Background:** *Multiple sclerosis (MS) is a severe neuroinflammatory condition, marked by a series of long-term disabilities. For this purpose, the chronically ill MS patients often require a noninvasive palliative approach to manage their neurological deterioration. A few major issues warranting palliative management include chronic pain, urinary or fecal incontinence, bed sores, and psychological support.*

**Methodology:** *This research was conducted as a qualitative study from September to October 2020. A total of 118 clinical articles were recognized through PubMed database using the following keywords: “Multiple sclerosis; Palliative management.” Out of these, 5 studies (including 4 randomized controlled trials and 1 systematic review) were incorporated into the final review while the studies based on literature review of the subject matter were rejected by the authors.*

**Discussion:** *All the four clinical trials indicated a markedly improved patient outcome at shorter follow-up durations following a course of palliative therapy. However, one study reported that at longer follow-up duration, the effectiveness of palliative care was not significantly better as compared to the control group. The only systematic review incorporated into the study failed to depict any major outcome variation between the patients receiving palliative therapy and those being offered other therapeutic measures.*

**Conclusion:** *Symptomatic care must be offered to the chronically debilitated MS patients through an integrated approach involving the neurologists, the palliative care specialists, the patient as well as their key family members. In addition, further clinical studies are warranted in this regard so as to justify the efficacy of palliative care in contrast to other modalities of therapy utilized for MS patients.*

**Keywords:** *Multiple Sclerosis, Palliative Care, Nervous System Diseases, Neurodegenerative diseases, Management.*

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## Background

Multiple sclerosis (MS) is a chronic neurodegenerative condition characterized by a long-term debilitation of neurological functions which is often attributed to autoimmune etiology. The worldwide prevalence of MS ranges from 2 to 165 cases / 100,000 population. The disease incidence has been estimated to be the highest in Northern America where 165 individuals per 100,000 population are diagnosed with MS annually (1). Considering the underlying neuroinflammation, the course of therapeutic intervention among such patients is mainly directed towards immunomodulation. An overactive immune system in MS can be neutralized by means of monoclonal antibodies, interferons, cytotoxic drugs, corticosteroids, and many other novel therapeutic agents (2).

It is noteworthy that due to an extremely severe neuromuscular dysfunction, patients diagnosed with MS are often in dire need of a chronic supportive therapy (3). To address the matter, it is customary to follow a standardized palliative care model for sake of a favorable prognosis. This palliative therapy aims at providing a patient with symptomatic care as well as psychological reassurance. Rather than implementing a one-sided plan of action, an ideal palliative care must involve an interaction between the patient, the neurologist, and the palliative care team so as to modify the course of treatment accordingly (4). All of these efforts must be directed towards prolonging a patient's overall life expectancy while increasing his/her comfort level. Among various palliative measures, management of chronic pain and fatigue is perhaps the most important. To adequately manage and advise the patients regarding urinary/fecal incontinence is another major aspect of palliative care. Other problems which might require attention include bedsores, constipation, dementia etc. Psychosocial support also remains an integral aspect of palliative management in MS (5, 6).

This review has been designed to determine the overall efficacy of symptomatic / palliative care offered to the chronically ill MS patients. Several notable authors have estimated the efficacy of palliative management for patients living with multiple sclerosis. Gomes et al have determined the role played by home-based palliative care in successful management of symptomatic disease among the MS patients. It has been found that such chronically debilitated patients while managed at home, are less likely to develop symptomatic overload (7). However, recent evidence has indicated that the medical community still bears some doubts pertaining to the suitability of this practice for treating a multitude of disabling symptoms in MS (8). This dubiousness has certainly necessitated further research into this debatable issue.

## **Methodology**

This review was carried out as a qualitative study from September, 2020 to October, 2020. The authors utilized the online medical database of PubMed Central, to search for those prospective / retrospective studies or systematic reviews which had assessed patient outcome secondary to a palliative therapeutic course in MS. The following keywords were used in the search process: Multiple sclerosis; Palliative management. A total of 118 articles were initially obtained which were filtered by using a thorough topic and/or abstract screening. The study focused on those articles which were based on either randomized controlled trials (RCTs) or systematic reviews pertaining to the subject. All those articles where the authors had performed a literature review of multiple sclerosis and/or its palliative treatment were excluded from the study. Following exclusion, a total of 5 articles (4 RCTs and 1 systematic review) were finalized and then incorporated in this research.

## **Discussion**

All the candidate articles were comprehensively studied by the authors and their major findings were subsequently summarized. Table 1 represents a qualitative analysis of this information.

## **Major findings**

### **Findings from RCTs**

#### **1. Can-do-treatment**

Jongen et al have characterized the efficacy of a variant of cognitive theory-based palliative treatment in chronic MS disease. This has been called can-do-treatment (CDT). It was reported that that an intensive 3-day social cognitive theory-based CDT improved the patients' self-efficacy at 1- and 3-month periods as compared to controls. However, it failed to show any significant improvement at 6-months follow-up time (9).

#### **2. Fast-track palliation**

A number of studies have been conducted to illustrate the effectiveness of a short-term palliative therapy in

MS, evaluated at a follow-up time of 12 weeks. In this regard, Edmonds et al have found a considerable improvement among those patients who were given a fast-track palliative care as compared to those who were offered standard therapeutic measures. In addition, palliative care has significantly helped reduce the workload on caregivers (10). In another trial, Higginson et al found comparable results for a fast-track palliative course (11). In addition, Hepgul et al have determined that a minimal duration integrated treatment plan is associated with a significantly better cost-effectiveness (12).

### Findings from systematic review

In a systematic review carried out by Latorraca et al, patients belonging to the palliative treatment and control group were both followed through a 6-month period. The authors concluded that there were no significant differences between the two groups in terms of change in their health-related quality of life and other adverse health events (13).

**Table 1. Effectiveness of Palliative Care in Multiple Sclerosis (MS)**

Study	Aut hors	Type of study	Purpose of study	Sample size	Variables	
					Independ ent variables	Dependent variables
Effect of an intensive 3-day social cognitive treatment (can do treatment) on control self-efficacy in patients with relapsing remitting multiple sclerosis and low disability: A single-centre randomized controlled trial	(9)	RCT	To assess the efficacy of can-do-treatment (CDT) protocol among patients suffering from MS.	158 MS patients	Can-do-treatment (CDT)	Self-efficacy of MS patients
Palliative care for people severely	(10)	RCT	To determine the role of a	52 MS patients	Fast-track palliative	Patient improvement as

affected by multiple sclerosis: evaluation of a novel palliative care service			novel palliative therapy for treating patients affected by MS.		care	determined by the Palliative Care Outcome Scale and Multiple Sclerosis Impact Scale
Evaluation of a new model of short-term palliative care for people severely affected with multiple sclerosis: a randomised fast-track trial to test timing of referral and how long the effect is maintained	(11)	RCT	To estimate whether short-term palliative care model proves efficacious for the patients diagnosed with MS.	52 MS patients	Fast-track palliative care	Patient improvement as determined by the Palliative Care Outcome Scale and Multiple Sclerosis Symptom Scale
Immediate versus delayed short-term integrated palliative care for advanced long-term neurological conditions: the OPTCARE Neuro RCT	(12)	RCT	To determine the definite role of short-term integrated symptomatic care in relieving MS symptoms.	350 patients diagnosed with MS, Parkinsonism, motor neuron disease etc.	Integrated palliative care approach	Patient improvement as shown by Integrated Palliative care Outcome Scale and other patient-related factors
Palliative care interventions for people with multiple sclerosis	(13)	Systematic review	To compare effectiveness of palliative care with routine therapeutic interventions for the individuals living with MS	146 MS patients	Palliative care intervention	Patient improvement as indicated by health-related quality of life and other patient-associated factors

The clinical trials discussed by the authors firmly insinuate that palliative care leads to a drastically improved quality of life among patients suffering from multiple sclerosis. However, one trial (9) failed to show any remarkable differences between the control and treatment groups at long-term follow-up, thereby indicating that symptomatic disturbances in control population tend to decline over the course of time. Surprisingly, the systematic review conducted by Latorraca et al (13) did not depict any remarkable efficacy of palliative measures when compared with standardized MS therapy.

These studies have also been plagued by a few limitations. Latorraca et al state that they could not evaluate the extent of improvement in MS patients in the following domains: body fatigue, mental depression and reduced cognitive performance, and poor motor performance etc. Similarly, other authors have characterized the limitations of their clinical trials as well. These include the following: limited sample population; shorter follow-up duration and possible inadequacy of various patient scoring criteria in estimation of patient outcome measures. However, the authors are of the opinion that these limitations do not necessarily outweigh the substantial findings of these studies.

Palliative care has been an integral component of cancer therapy, especially when it comes to the management of unresectable tumors. However, its role in the integrated clinical management of neurodegenerative conditions has been only recently recognized. MS clinically persists as a severely debilitating, irreversible disorder and therefore, it is only logical to add palliative care as an interventional option for its efficacious management (14). In addition, a well-organized palliative care system needs to be devised for the purpose of counselling and reassuring patients as well as their families (15).

## **Limitation**

The findings of this study, although supported by credible scientific evidence, are limited by a smaller number of studies evaluated by the researchers.

## **Conclusion**

Effective management of MS patients requires an integrated palliative therapeutic approach that includes open communication between the patient and the medical team. Knowing that MS is an irreversible, extremely disabling disorder, the only interventional option for successful management is palliative care.

Thus, a well-structured palliative care system must be developed to provide patients and their families with optimal counselling and reassurance.

An integrated approach combining neurologists, palliative care specialists, the patient, and important family members is necessary to provide symptomatic care to people with MS who are chronically disabled. To support the effectiveness of palliative care relative to other therapeutic modalities used for MS patients, more clinical research is also necessary in this area.

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