

Nursing care (palliative medicine) in patients with neuropsychiatric disorders

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ABSTRACT

Background and Purpose: Palliative medicine is a special status focusing on the quality of life of patients suffering from special or advanced diseases. Palliative medicine can be helpful at any stage of the disease, including the diagnosis. Thus, the present study aims at reviewing the application of palliative care in mental disorders. **Method:** In the present study, as many as 1,149 studies were found in the period of 1985 to 2018 by searching on different websites including Medline, Embase, ProQuest, Global Health, GoogleScholar, and Scopus. As many as 53 studies having to do with mental disorders were found, and more specifically, as many as 36 articles related to palliative medicine were applied. **Findings:** Reviewing the related literature indicates that the care needs of mental disorders patients are quite complicated. The findings indicated that predicting the complications of the disease, as well as advanced planning in terms of caring for these patients, are of significant importance. The findings indicated that over the last decade two palliative care models have been developed: integrative and consultative. **Conclusion:** With the growth development of palliative care in developed countries, the knowledge of palliative care can be shared with the nurses and practitioners of neurological diseases, and this knowledge can be applied to palliate and reduce the pains and sufferings of the patients and their families.

Keywords: Caring needs, mental disorder patients, nursing, palliative care

Introduction

Palliative care has a special status for the aim of diagnosing, predicting, and palliating the pain of special disease patients and their families.^[1] In terms of comprehensive care, eight domains have been identified. These domains include Structure and Processes of Care; Physical Aspects of Care; Psychological and Psychiatric Aspects; Social Aspects of Care; Spiritual, Religious, and Existential Aspects of Care; Cultural Aspects of Care; Care of the Patient at the End of Life; and Ethical and Legal Aspects

of Care.^[2] The main aim of palliative care is improving the quality of life of the patients and their families, evaluating the caring aims, and regulating the treatment options or aims.^[3] Over the last decade, palliative medicine has progressed to a significant level. In 2015, as many as 67% of the hospitals in the United States provided palliative services with 50 beds or more. As for the large hospitals having 300 beds or more, more than 90% of them provided palliative care programs.^[4] This process has resulted in increased longevity to some extent, and it is associated with the prevalence of chronic diseases.^[5] Moreover, reviewing the literature of palliative cares in nursing indicates that these kinds of care result in reduced long-term sadness and decreased post-traumatic stress disorder in the patients and their families. Palliative care has

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also proved to be helpful for the health care system. Palliative care has resulted in the improved perception of the symptoms and patient's/family's satisfaction, and they have reduced the admissions and unnecessary processes in old patients.^[6-8] Thus, the present study aims at reviewing the application of palliative care in different mental disorders.

Method

The studies conducted on palliative care for mental disorders (Parkinson's disease, dementia, amyotrophic lateral sclerosis (ALS), brain tumors, stroke, and acute neurological diseases) have been investigated in the present study. These studies have been conducted from 1985 to 2018. In the present study, the searching procedure was conducted in different websites including PubMed, Science direct, Medline, Embase, Global Health, GoogleScholar, and Scopus by using the keywords such as care, nursing, palliative care, caring needs, quality of life, end of life care, Parkinson's disease, dementia, ALS, brain tumors, stroke, and acute neurological diseases. Among 1,149 studies found, as many as 53 studies were used in the present review article. Among these 53 studies, as many as 36 studies were completely related to palliative care. The procedure of finding the related studies has been shown in the Diagram 1.

Clinical needs in neurological diseases

Neurological diseases are often progressive and incurable, and they are commonly associated with undesirable complications

and mortality. The treatment of most of these diseases is conducted by applying palliative care. The emphasis is mainly put on managing the symptoms, maintaining mobility, adjusting the individual with reduced physical performance, and supporting the caregivers. In spite the widespread attempts made to provide high-quality cares in these patients, reviewing of the related literature indicates that these patients are in need of palliative cares. Integrating the main principles of hospital cares with palliative care programs is likely to improve the quality of life in these patients. In the present article, it has been attempted to investigate more common diseases that need higher levels of palliative care. This approach is likely to be helpful for patients suffering from severe neurological symptoms and their families.

Parkinson's disease

Parkinson's disease is a long-term disease that is associated with progressive weakness and disability in the muscles and brings about disorders in the patient's balance, mobility, speech, and cognition. Very often, in the primary stages of the disease, the patients respond to dopamine replacement therapy. As the disease progresses, these patients experience more non-motor movements that made it harder to bear the disease.^[9] Parkinson's disease patients and their caregivers assert that they are in need of special needs during the disease.^[9,10] The common non-motor symptoms include orthostatic hypotension, swallowing problems, psychological problems, pain, and constipation.^[11,12] Edmonton

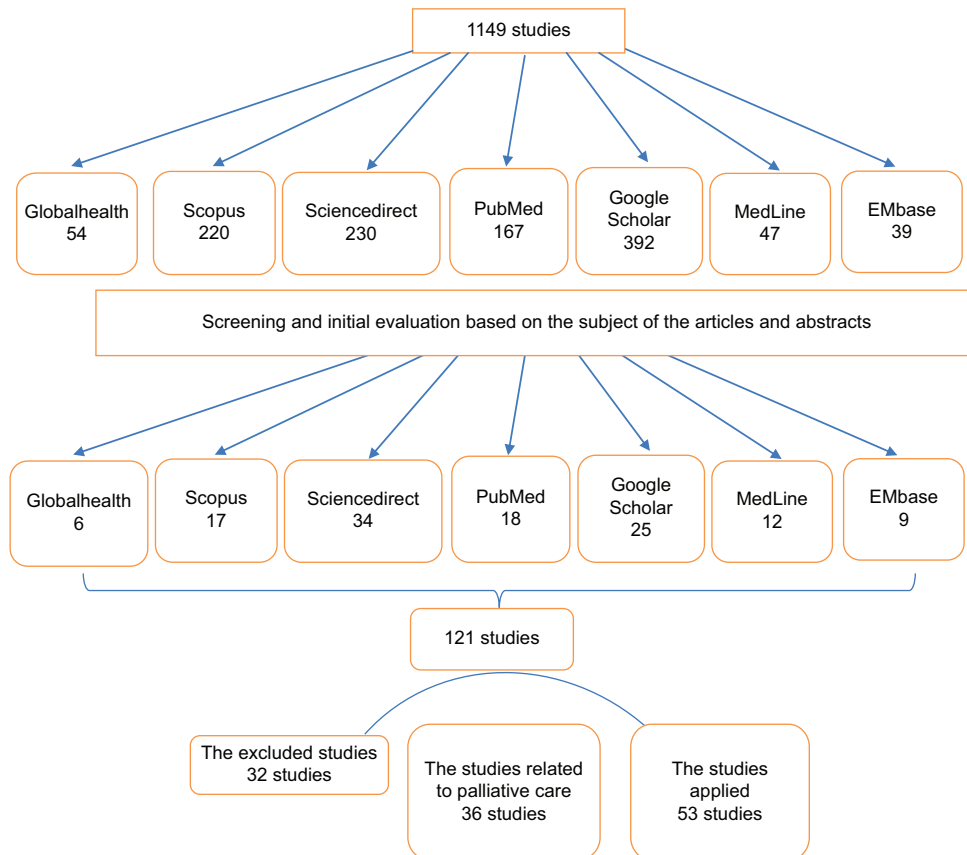


Diagram 1: The flowchart of the studies investigated in the present study

Symptom Assessment Scale (ESAS) has been developed to be used in Parkinson's disease and has been applied in Toronto and Ontario for assessing the special symptoms of Parkinson's disease.^[10] It was possible to implement this scale in the palliative care program and provide some data for guiding the palliative interventions related to the prevalent symptoms such as swallowing problems, constipation, anxiety, pain, muscle stiffness, and drowsiness. This scale helped to conduct medicinal regulations and remedies related to Parkinson's disease. Moreover, this scale provided a reference for the daily programs offered by speech pathologists, psychiatrists, nutritionists, other kinds of therapists, and other medical and surgical specialists. Applying ESAS in patients suffering from Parkinson's disease was improved in later tests, and this indicates that palliative interventions have been useful on this group of patients. In addition to controlling the symptoms, it was attempted to obtain more information on the disease at the early stage of the disease from the patients and their caregivers.^[13,14] In the qualitative studies conducted on the Parkinson's disease patients and their families, the subjects that have been frequently discussed included disease prognosis and options to support and improve care planning.^[13,15] In their study, Boersma *et al.* have indicated that the growing concerns over the cognitive and functional status in the future and the progress of the disease symptoms have made Parkinson's disease patients feel more isolated.^[13] The study conducted by Tuck *et al.* (2015) indicated that by adopting decisions over their future care some of the patients intended to maintain their autonomy because they are likely to suffer from cognitive problems.^[13]

Dementia

As for the prediction of losing cognitive skills, decision-making capability, and the procedure of dementia, the doctors need to speak with the patients as well as their caregivers and decision makers.^[16] The common problems in dementia include frequent infections, hospitalization, and eating and swallowing problems.^[16] Other symptoms that are likely to be seen at the end of life include pain, dyspnea, and panic.^[17] The programs related to the management of these aspects of the disease can be created through discussing caring and preventive issues. The review of the related literature indicates that caregivers have participated in discussions related to prognosis and determining caring priorities are likely to give more attention to the quality of life and comfort of their patients.^[16] Making decisions over nutrition options, transferring nursing specialists for these patients, and providing health care need to be considered. In advanced dementia, applying gastrostomy tubes for swallowing problems and taking food will neither prevent breathing nor improve wound healing and functional performance.^[18] The studies indicate that in patients suffering from dementia, there is an increase panic. Thus, patients need to be limited, and this limitation includes their daily interactions. Moreover, the progress of the disease and using feeding tubes and respiratory equipment in patients suffering from dementia indicate that there is an increasing need for further attempts toward a better understanding of cooperative decision-making processes for the treatment and

care of these patients.^[19,20] In the final years of life, being fed by caregivers encourages these individuals.^[19] High-quality home care and nursing for dementia patients can help the patients palliate their disease.^[21]

Amotrophic lateral sclerosis

ALS is one of the worst diseases because it rapidly reduces the motor and breathing functions of the patients, and it results in severe loss of independence and disability. Thus, numerous programs can be applied to provide palliative care for these patients. These patients experience numerous symptoms including hypersalivation (also called ptyalism or sialorrhea), spasticity, pseudobulbar affect (uncontrollable episodes of crying and/or laughing), dysphagia, weight loss, and respiratory failure, and they all call for immediate treatment by the care team.^[22,23] Maintaining social interactions and mobility are the fundamental aspects of caring for these patients that can improve their total quality of life.^[22,23] The preparation of the individuals and caregivers to reduce the problems of swallowing and respiratory function is necessary. Although the patients might disagree over selecting the treatment in advanced ALS, it is likely that using feeding tubes before the emergency status helps them survive some more months.^[24] When their critical functional capacity is less than 50% or when the patients suffer from respiratory muscles weakness and musculoskeletal system defect, non-invasive positive pressure breathing is recommended for them.^[25] In addition to help the patients survive longer, non-invasive positive pressure breathing is likely to help the patients increase their quality of life.^[26,27] The initial studies conducted on prognosis, invasive methods, and transferring the patients to the wards where special care is provided for the patients is likely to help the patients have sufficient information and time to make appropriate decisions.^[28] Other patients suffering from neuromuscular problems such as Duchenne muscular dystrophy and spinal muscular atrophy that are similar to ALS patients might receive palliative considerations as well. Moreover, it can be stated that palliative treatment and care are likely to increase the longevity of patients suffering from severe myopathy and muscular dystrophy and they can help the caregivers manage the symptoms and adopt appropriate decisions for these patients by conducting more studies.^[29,30]

Brain tumors

There are numerous evidence that palliative care has helped cancer patients to a great deal so that they have managed the symptoms of their disease and promote their quality of life.^[31,32] In spite the prevalent physical and mental symptoms related to tumor growth and the effects of treatment, few studies have been conducted on patients suffering from brain tumors.^[33,34] Over the course of the disease especially at the end of life, patients suffering from severe gliomas have symptoms such as headache, swallowing problem, seizure, drowsiness, establishing communication problem, and attention deficit, and they are in need of more management.^[35] In a study conducted by Diamond *et al.* (2015), among 160 primary brain tumor patients hospitalized in a big city and died over 4 years, as many as half of them

referred to the intensive care units within 14 days before their death. The findings indicated that late referral to the intensive care units reduced the patients' quality of life to a significant level.^[36] In a retrospective study, Gofton *et al.* (2012) reported reduced stepping performance and instability, reduced cognition and personality changes, seizure, and encephalopathy as the primary symptoms of hospitalizations in patients suffering from primary brain tumors and metastasis.^[37] There are numerous challenges in providing palliative care for brain tumor patients for two main reasons; the cognitive function of the individuals may fail, and given the therapeutic nature of cancer, the treatment may last until the end of chemotherapy, and palliative care cannot be properly provided for these patients.^[38]

Stroke

Although their severity and course of disease is variable, stroke patients are in need of essential post-stroke palliative care.^[39,40] It seems that symptoms such as pain, fatigue, depression, anxiety, and swallowing problem need to be identified at first; these symptoms are likely to affect the primary attempts made for rehabilitation. The findings of the study conducted by Holloway *et al.* (2010) in a center indicated that palliative care consultations provided for stroke patients are different from those provided for other patients.^[41] It seems that they are not able to make medical decisions such as receiving artificial nourishment, mechanical ventilation, and tracheotomy. Stroke is the fifth leading cause of death in the United States,^[42] and it is recognized as the leading cause of serious, long-term disability.^[43] It has been estimated that as many as 15–30% of the patients will be disabled permanently, and as many as 20% of them need long-term cares in the first 3 months after stroke.^[39] Given these statistics, the doctors need to determine the medical priorities of post-stroke period, so that these priorities will be applied as appropriate guidelines for the patients and their caregivers.^[44] Palliative care can be provided for the patients and their families by primary medical teams of stroke and palliative care providers.^[45,46] In stroke, the key palliative care includes predicting cases related to stroke, mastery over cases that call for critical decisions, developing caring purposes, managing biopsychosocial symptoms, providing end of life care, and providing appropriate post-death services.^[45]

Providing intensive cares for mental neurological patients

The initiation of the disease is commonly acute in patients suffering from special diseases, and this calls for immediate and serious treatment and intensive cares. The family members of these patients often deal with decision-making problems over the treatment options and caring purposes. When the patients are discharged from the hospital, they are likely to experience degrees of inability that affect their daily life. Palliative care methods help complicated decision-makings (given the new role of the caregivers), managing the symptoms and goal setting, and understanding the realities of the new status.^[47] Creutzfeldt *et al.* (2015) conducted a study to encourage the intensive care unit (ICU) team to identify the palliative care needs in the patients

of neuro-ICU and their families and the potential ways to fulfill these needs. They applied a daily screening tool to assess the physical, mental, and social needs of the patients.^[48] The number of family sessions increased in neurological patients screened for palliative care, and after assessing the caring purposes, these patients demanded to receive consultations related to palliative care.^[48,49] From the 62% of the neuro-ICU patients diagnosed to have a caring need, it was recognized that most of them and their families were in need of social support. Thus, assessing the caregivers is of significant importance. For diagnosing patients with special needs that are likely to receive palliative care, appropriate screening tools, checklists, and trigger criteria can be applied. For example, in patients with special conditions of strokes, applying special clinical and radiography findings can be helpful.^[50] Trigger criteria have been suggested in the consultations related to palliative care for metastatic cancer patients who are in need of mechanical ventilation, patients who require long-term hospitalization, older patients suffering from chronic medical problems, and survivors of cardiac diseases.^[50] Trigger criteria can be applied for both analysis and frame-by-frame search of the events.

Palliative care models in neurological diseases

Palliative care is provided through outpatient counseling services, outpatient palliative care units, outpatient clinics, home visits, and hospital special services.^[51] Palliative and supportive care clinics related to neurological diseases have recently focused on the complicated needs of the patients and their families. These clinics are interdisciplinary and have a more comprehensive approach toward caring, religion, spirituality, physical symptoms, social support, and caregivers' assessment.^[52] The models recommended in the studies investigated include 1. Integrating palliative care with primary care services for the normal management of the program in patients suffering from acute and chronic diseases (known as Integrative Model); and 2. Consultative model that includes providing palliative care counseling for patients who are in need of palliative needs.^[53] According to the studies conducted, it seems that the ideal model is a combination of these two models. The primary palliative care is suggested by the doctors who have comprehensive knowledge about the process of the disease as well as palliative care specialists who are greatly specialized about pain assessment and reduction.^[48,53]

Conclusion

The neurological conditions bring about difficult, complicated, and inappropriate symptoms. The variable courses of the disease, as well as poor predictions, affect the patients as well as their families and caregivers. Patients with neurological diseases such as Parkinson's disease, dementia, ALS, brain tumors, stroke, and acute neurological diseases require special attention during primary care. They are also in need of palliative and specialized nursing care at later stages of the disease. The caring needs of these patients are quite complicated, and the caring services need to be provided in such a way that their pains and sufferings are healed physically, psychologically, socially, and mentally. The

primary discussion over the caring purposes, predicting the complication of the disease, and planning progress of the care provided are of significant importance; the discussion of these issues are likely to provide appropriate guidelines for the medical decision-makings adopted and help the patients maintain their independence in spite their cognitive and functional failures. Very often, patients suffering from neurological disorders have complicated needs, and palliative approaches can help them. Focusing on primary interaction in the course of disease, frequent symptoms, treatment options, and prognosis is of significant importance, and they are likely to be helpful for coping with the concerns the patients and their family's experience. The joint decision-making over the critical decisions along the continuum of the disease is an indispensable part of doctor-patient relationship, so that it is made sure that the care provided conforms to the patients' priorities. Conducting further studies is required to establish appropriate methods and models for palliative care, and this can help the neurological patients' caregivers and families to manage and plan the method of providing cares. With the rapid development of palliative care in developed countries, the knowledge of palliative care can be shared with the nurses and practitioners of neurological diseases.

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Conflicts of interest

There are no conflicts of interest.

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