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Role of palliative care at the terminal stages of life

Dr. Anil Batta
Assoc. Professor, Department of Medical Biochemistry, Govt. Medical College, Amritsar, Punjab, India

Abstract
Palliative care (pronounced pal-lee-uh-tiv) is specialized medical care for people with serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment. Palliative care teams specialize in treating people suffering from the symptoms and stress of serious illnesses such as cancer, congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), kidney disease, Alzheimer's, Parkinson's, Amyotrophic Lateral Sclerosis (ALS) and many more. This type of care treats pain, depression, shortness of breath, fatigue, constipation, nausea, loss of appetite, difficulty sleeping, anxiety and any other symptoms that may be causing distress. The team will help you gain the strength to carry on with daily life. In short, palliative care will help improve your quality of life. Palliative care teams specialize in treating people suffering from the symptoms and stress of serious illnesses such as cancer, congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), kidney disease, Alzheimer's, Parkinson's, Amyotrophic Lateral Sclerosis (ALS) and many more. This type of care treats pain, depression, shortness of breath, fatigue, constipation, nausea, loss of appetite, difficulty sleeping, anxiety and any other symptoms that may be causing distress. The team will help you gain the strength to carry on with daily life. In short, palliative care will help improve your quality of life. The palliative care team will also spend time talking to you and listening. They will make sure you understand all of your treatment options and choices. By deeply exploring your personal goals, the palliative care team will help you match those goals and options. They will also make sure that all of your doctors are coordinated and know and understand what you want. This gives you more control over your care. Palliative care teams are specialists who work together with you, your family and your other doctors. They provide an extra layer of support when you need it most. In addition to treating your symptoms, the palliative care team spends as much time as necessary communicating with both you and your family. They support you every step of the way.

Keywords: kidney disease, alzheimer's, parkinson's, amyotrophic, cancer, congestive heart failure

Introduction

Objectives

Study objectives were [1] to assess inpatient hospice clinician attitudes towards the benefits of benzodiazepines for various indications and [2] to compare these attitudes to current clinical recommendations and literature.

Methods

A survey was developed and distributed to hospices with inpatient units nationwide. Results were analyzed, then compared to current clinical guidelines. Participants were asked to indicate their level of agreement.

Results

Of 150 surveys returned, 128 surveys were completed. For anxiety, 80% of participants agreed that benzodiazepines were beneficial for restlessness, dyspnea 77%, insomnia 68%, dying process 65%, agitation 57%, nausea 54%, hyperactive delirium 42%, and severe pain 38%. Nurses found benzodiazepines beneficial for more indications than physicians. Over 50% reported benzodiazepines on their order sets for agitation, insomnia, acute anxiety, chronic anxiety, chronic panic, restlessness, seizures, and withdrawal. Among physicians, 39% believe that benzodiazepines are overused within their own hospice. A literature review found very limited evidence of overall benefit from benzodiazepines for the symptoms listed above. In addition, this revealed significant evidence for risks and harms from benzodiazepines, particularly in patients at risk for delirium.

Conclusions

Benzodiazepines are viewed favorably by most hospices for various indications, despite little supportive clinical evidence along with significant potential for harm.

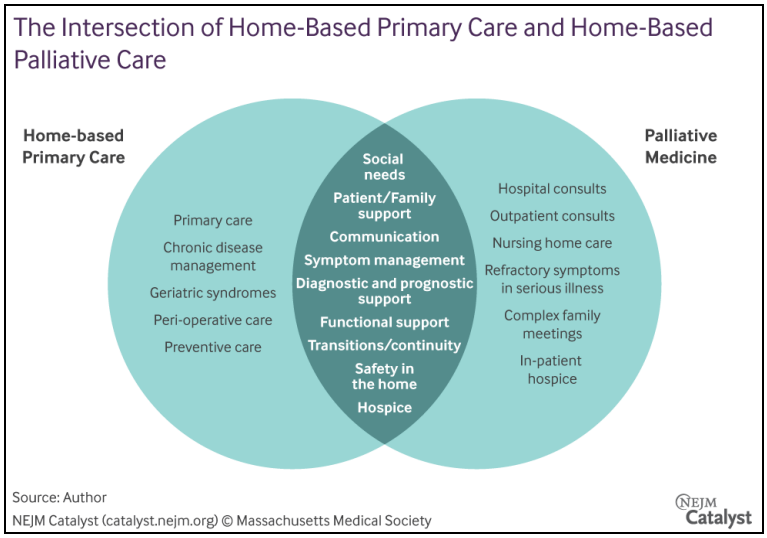

Fig 1: Home based palliative care

Introduction

Models of care

The traditional medical treatment model has become dichotomous, leading physicians to provide curative or aggressive treatment initially and to initiate comfort care only when other measures have failed. Palliative medicine establishes goals to relieve suffering in all stages of disease and is not limited to comfort care or end-of-life care (Figure2) [3]. The terms palliative care and hospice care are sometimes used interchangeably. According to the National Quality Forum, hospice care is a service delivery system that provides palliative care/medicine when life expectancy is 6 months or less and when curative or life-prolonging therapy is no longer indicated [4]. Therefore, it is important to distinguish that although hospice provides palliative care, palliative care is not hospice. Not all available therapeutic palliative care modalities are provided within the hospice service delivery system.

The concept of total pain

The alleviation of suffering is an essential goal of medical care. To treat it, however, providers must first recognize pain and suffering.5 Saunders first described the concept of total pain (Table 1) [6] and interaction among the various sources of pain and Suffering.7 Total pain is the sum of the patient's physical, psychological, social, and spiritual pain. This concept is central to the assessment and diagnosis of pain and suffering. Because psychological distress, lack of social support, and physical pain are associated, 8 treating a patient's total pain is imperative, especially at the end of life. Optimal pain relief will not be possible unless all the elements of total pain are addressed. Clinicians should utilize other members of the multidisciplinary team, such as social workers and chaplains, to better treat suffering related to the different domains of total pain.

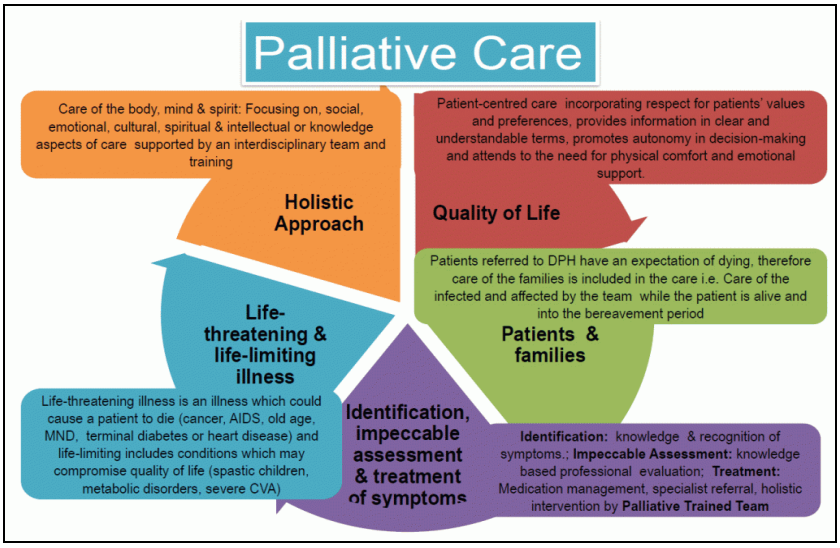

Fig 2: Palliative care

Managing common physical symptoms

Patients near the end of life may experience extreme symptoms that include physical, spiritual, and psychosocial suffering. Preventing and managing these symptoms while

optimizing the quality of life throughout the dying process is the goal of palliative medicine.[9] Factors important to seriously ill patients include adequately controlling pain and other symptoms, avoiding prolongation of the dying process, achieving a sense of self-control, finding meaning in life, and relieving the care burdens of family and loved ones while strengthening and completing those same relationships.[10] As death becomes nearer, the symptom burden increases while the patient and family tolerance of physical and emotional stress decreases. At this time, primary palliative care interventions should take precedence, and the focus on restorative care should decrease. The triggers for the shift to palliative care include the following four symptoms. Physical Pain is one of the most prevalent symptoms near the end of life [5]. Unrelieved pain can be a source of great distress for patients and families and exacerbate other symptoms. Therefore, the adequate management of pain at the end of life is imperative. Although opioid analgesics are the standard of care for treating moderate to severe pain in patients with advanced illness, the false fear that opioids induce respiratory depression and hasten death is a major barrier to their use at the end of life. However, both effects are uncommon when opioids are given at appropriate doses. Clinicians who care for the chronically ill and for those at the end of life should acquire competency in pain management.[11] Dyspnea, the subjective sensation of breathlessness, is a frequent and distressing symptom, particularly in dying patients. Opioids and benzodiazepines are the most widely prescribed medications for treating dyspnea. As death approaches, a clinician may use continuous infusions to manage symptoms and relieve suffering if scheduled or as-needed doses are not adequate. The clinician should continually assess the patient and make adjustments that will control symptoms.

Methods

The survey was available for completion from March to May 2016. Once all surveys were received, basic statistical analysis was performed[2]. The average and range of attitudes were assessed for multiple questions. Responses were broken down to compare different response groups with total agree versus total disagree for each individual question. Using the Fisher exact test, these groups' total responses were used to calculate *p*-values. Responses were analyzed to see if there were significant differences between the following groups: clinical role[3]. A literature search was performed seeking evidence from clinical reviews and randomized controlled trials regarding benzodiazepine use in palliative and hospice patients. Other searches of "benzodiazepines" with either "hospice" or "palliative" together with various symptoms were used, and pertinent references within relevant articles were also evaluated. Review of the Cochrane database for "benzodiazepines" and various symptoms for evidence-based reviews as well as the National Guidelines Clearinghouse for relevant guidelines were performed and reviewed. Finally, because of the paucity of studies in hospice or palliative care, a more thorough literature review was performed for "benzodiazepines" with either "elderly," "geriatric," or "intensive care" (to represent populations similar to hospice) together with various symptoms. Benzodiazepines are a class of drugs widely used in palliative care. In the last week of life 82% of the patients receive midazolam at least once[8]. Benzodiazepines can cause cognitive impairment, somnolence, loss of memory, and dependence [7]. Their use can make accurate assessment of depression and psychological management of anxiety more difficult. When administered together with opioid analgesics, or with other psychotropic drugs, there may be additive adverse effects at the central nervous system level thus causing a worsening of the morbidity[6]. This study was structured with the aim to evaluate the number and the characteristic of the patients, the nature of and indications for the use of benzodiazepines and other psychotropic medication prescriptions [7]. The length of benzodiazepine administration, the association with other drugs such as opioids and antidepressants and their efficacy and tolerability were also evaluated. Starting 29th October 2015 the previous 100 consecutive patients who ended their hospice care either in hospice or at home were evaluated[5]. All patients had cancer, their median age was 73 years and 75% were male. Seventy percent of the patients studied received benzodiazepines (70/100); about 8% of them were already being prescribed benzodiazepines at time of referral; about 50% of them received the drugs during their time in palliative care and received prescriptions for 69 benzodiazepines, Many patients on antidepressants and/or on anti-psychotropic drugs (28%) received a benzodiazepine treatment. From the "notes" in the clinical charts anxiety/agitation was considered the most frequent cause followed by distress, sleep disturbance and dyspnea. Diazepam, lorazepam and alprezolam were the benzodiazepines most frequently used with a recorded effectiveness of 70%. The number of patients on benzodiazepine increased to 50% [8] No significant adverse effects were recorded. Benzodiazepines are a class of GABA agonist medications used extensively by hospice providers internationally for a variety of symptoms [6]. Unfortunately, research performed in hospice populations regarding benefits and harms of benzodiazepines is limited. As a result, best practices regarding benzodiazepines for hospice patients are unclear. [6], S So it is critical to assess how these medications are being perceived and used compare this to the actual evidence regarding benzodiazepine use in both the hospice population and in similar populations, such as the elderly and critically ill [9].

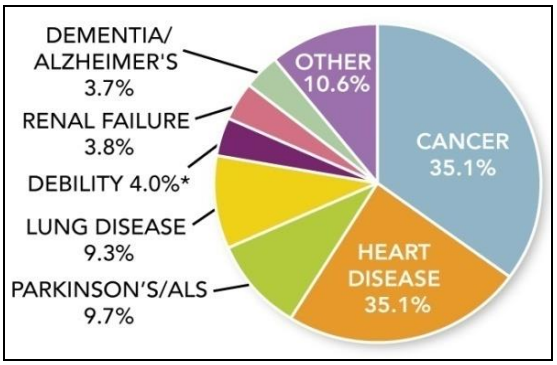

Fig 3: Unity Hospice & Palliative Treatment

Discussion

Background: Benzodiazepines are widely used in palliative care, but few studies have attempted to study their use. Aim:

To determine the frequency and nature of benzodiazepine prescribing in a palliative care setting. Method: The notes of a consecutive series of 100 patients who had died or been discharged from the hospice were studied. Demographic, illness and prescription data were noted. The indication for the administration of benzodiazepines, their effectiveness and any adverse effects were recorded. Results: Notes were found on 93 patients. Some 54 (58%) were prescribed benzodiazepines either by the hospice or their General Practitioner. Younger patients and those on opioids or anti-psychotics were more likely to be prescribed benzodiazepines [9]. Most administration of benzodiazepines occurred within the last three weeks of life in response to symptoms of anxiety or less specific distress. Conclusions [8] A relatively high proportion of patients were prescribed benzodiazepines. The role of benzodiazepines at different stages of palliative care merits further study. (PsycINFO Database Record (c) 2009 APA, all rights reserved) (Journal abstract) [11]. Of the 100 surveys distributed, 143 responses were returned, with 128 completing all portions. Of the hospice work, 66 (78%) worked an average of 15 hours/week in a hospice inpatient unit and 68 (80%) worked an average of 14 hours/week in home hospice. The response summaries for each question are listed in Figures 1 and 2 and Table 1. Of note, majorities of respondents agreed that benzodiazepines were beneficial for chronic anxiety and chronic panic disorder, dyspnea, insomnia, nausea and/or vomiting, agitation, terminal delirium, and the dying process. Majorities disagreed that benzodiazepines provide benefit when used for hypoactive delirium and sun downing in dementia. The responses were more evenly split for hyperactive delirium, severe pain, and acute paranoia. Regarding order sets, the majority of respondents reported that benzodiazepines were on their order set for acute anxiety (96%), chronic anxiety, agitation, insomnia, panic, restlessness, seizure, and withdrawal, with smaller numbers reported for others [12].

Conclusion

In the recent past, benzodiazepines were heavily used for sedation in the ICU setting and were used commonly within the geriatric population. However, following multiple studies involving ICU patients, other medications and strategies have largely replaced benzodiazepines in the intensive care setting [3, 7]. At the same time, various studies have demonstrated significant harms in the elderly and those at risk for delirium. Guidelines increasingly recommend avoiding use in those populations as well [5, 6]. Until more hospice-oriented evidence is available, strong regard should be paid to studies within the intensive care and geriatric populations, which are similar in many ways to the inpatient and home hospice populations, respectively [9].

This study demonstrates that large percentages of hospice clinicians view benzodiazepines as beneficial for a wide range of symptoms. Specifically, majorities of respondents agreed that benzodiazepines were beneficial for chronic anxiety and chronic panic disorder, dyspnea, insomnia, nausea and/or vomiting, agitation, terminal restlessness, and the dying process, with pluralities reporting benefits for hyperactive delirium, severe pain, and acute paranoia. In addition, the majority of respondents reported that benzodiazepines were on their order sets for acute anxiety, chronic anxiety, agitation, insomnia, panic, restlessness, seizure, and withdrawal, with substantial minorities for most other problems [13]. It is reasonable to infer that use of benzodiazepines for these indications is common practice among hospice providers in the United States. A special focus of this study was on benzodiazepines in delirium [7]. Given that delirium is frequently underdiagnosed, [4] the authors considered some symptoms, specifically restlessness, agitation, acute paranoia, and the dying process, to be potential proxy responses for patients who may have delirium. Overall, large percentages of hospice clinicians in this survey reported benzodiazepines as beneficial in many patients who may have delirium [13]. Given the cornerstone study within the palliative field, [31] available literature [3], and the evidence suggesting that benzodiazepines may cause or worsen delirium [9], the numbers of positive responses are striking. In addition, considering that antipsychotics are considered first-line treatments [4, 5], it is also remarkable that only 45% of those reporting benefit from benzodiazepines in hyperactive delirium indicated that combination with an antipsychotic would provide added benefit in treatment of delirium. Weaknesses of this study include the limited response rates leading to a relatively small sample size, with most questions having an estimated margin of error of 9% [2]. This study shows that many hospice physicians and most hospice view benzodiazepines as beneficial treatments for a wide variety of symptoms including patients with delirium. However, the accompanying review largely failed to find literature that supports these views, and instead found evidence that benzodiazepines should be avoided in most patients at risk for delirium. This apparent disconnect between attitudes toward benzodiazepines and available research in similar populations suggests that these attitudes rely primarily upon anecdotal experience rather than clinical evidence of efficacy [4, 6]. The fact that hospice patients generally have a limited life expectancy and a high risk of delirium requires us to be particularly cognizant of potential harms from medications and to ensure the best-quality evidence-based care. This study demonstrates an urgent need for high-quality hospice and palliative-based research to evaluate the benefits and harms of benzodiazepines in this population, and to determine appropriate indications for their use. It also reveals the need to ensure individual hospice physicians and nurses are aware of and following current best practices. In the meantime, it would be reasonable to utilize restraint with benzodiazepine prescribing, particularly in patients at risk for delirium, and to consider adoption of strategies used in the geriatric and intensive care settings to minimize the need for these medications.

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