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PALLIATIVE CARE FOR PATIENTS WITH TUBERCULOSIS : NEED OF THE HOUR

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Abstract

BACKGROUND : Palliative care (PC) is a specialized medical care that aims to relieve suffering and improve the quality of life for patients and their families facing life-threatening illnesses, including tuberculosis (TB). Palliative care can be provided alongside disease-directed treatment, beginning at diagnosis and continuing until end of life. A multidisciplinary team is necessary for Palliative care for Tuberculosis patients , including doctors, nurses, psychologists, social workers, nutritionists, and physiotherapists. Palliative care opportunities in TB include managing physical symptoms such as dyspnea, pain, cough, hemoptysis, respiratory secretions, insomnia, anorexia-cachexia, and fatigue. Psychological support is also crucial, as the diagnosis of TB can cause feelings of rage, despair, grief, anxiety, and dread. Social support, provided by TB social workers, can assist patients with TB in treatment compliance, linking to healthcare centers, and financial assistance. Spiritual concerns can also affect coping, and spiritual activities have shown to improve emotional control in TB patients. Nutritional support plays a crucial role in recovery from TB, and co-morbidities such as diabetes and immunosuppression can increase the need for PC. End of life care is provided during the final hours, days, or months of a person's life, and palliative care services extend beyond death to bereavement services for families. Challenges in providing PC in TB include a lack of awareness and misconceptions about PC, the need for advocacy for primary palliation, and the limited availability of medical practitioners with palliative care training. Further studies are needed to guide physicians in the role of PC in TB.

KEYWORDS : Airborne infection control, Tuberculosis, Prevention, Implementation

INTRODUCTION

Palliative care (PC) is a specialized medical care delivered by a multidisciplinary team aimed at relieving suffering and improving the quality of life (QoL) for patients and their families facing life-threatening illnesses.[1] There is a common misconception that PC is meant for patients who have exhausted all treatment options or are terminal.

However, PC can be provided alongside disease directed treatment regardless of the age and prognosis, beginning at diagnosis of the illness right until end of life and beyond. PC encompasses identification and treatment of pain and other physical, psychosocial and spiritual symptoms experienced by patients and their caregivers.

Palliative care is well established in oncology and in other life-limiting diseases like neurological conditions, heart failure, end stage liver disease, chronic kidney disease and respiratory diseases.[2] Utilization of palliative care in infectious diseases like tuberculosis, malaria and rabies is evolving and not well accepted.

The goal of palliative care is to relieve suffering which aligns with the vision of the end TB strategy i.e to zero suffering due to TB.[3]

Even though tuberculosis can be cured, drug-resistant tuberculosis (DR-TB), which includes multidrug-resistant(MDR-TB) and extensively resistant TB (XDR-TB), is becoming more common and is prone to longer treatment duration and potential treatment failure. Palliative care demands may arise even in patients with drug-susceptible tuberculosis, patients with several co-morbidities and extra-pulmonary tuberculosis deserve specific attention.[4]

They often require palliative care due to their significant symptom burden. A trained multidisciplinary team made up of doctors, nurses, psychologists, social workers, nutritionists, and physiotherapists is necessary for many reasons, including symptom control, sensitive communication to establish disease understanding, managing drug side effects, maintaining adherence to treatment, minimizing social stigma associated with TB, education on nutritional requirements, and facilitating pulmonary rehabilitation.(5)The following sections elaborate upon the PC opportunities in patients suffering from TB in the physical and non-physical domains.

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PHYSICAL SYMPTOMS :

Patients with tuberculosis experience respiratory symptoms like dyspnea, cough, hemoptysis and chest pain and non-specific symptoms like fever, insomnia, anorexia, fatigue, night sweats etc.

1. Dyspnea : It is a common complaint as a result of lung parenchymal damage, spontaneous pneumothorax, or pleural TB presenting with effusion. Reversible causes like pleural effusion can be managed with thoracocentesis. Non pharmacological techniques like handheld fan directed to face decreases the sensation of breathlessness, pursed lip breathing, propped up position or forward leaning position can aid in reducing dyspnea. Conventional techniques like bronchodilators help when obstructive airway features co-exist. Opioids for refractory dyspnea can be used to decrease respiratory drive. Low dose morphine tablet 2.5 mg three times a day can be used. Associated anxiety can be tackled with anxiolytics I.e benzodiazepines.[6]

2.Pain : In TB, pain can occur due to various reasons. The involvement of pleura can give rise to chest pain, while the presence of back pain should raise suspicion of Pott's spine. TB meningitis can provoke headaches while TB arthritis can lead to joint pain. Insertion of an intercostal drainage (ICD) tube is a source of procedure-related pain . Identifying the type of pain is crucial for effective management. While ICD pain, and bone pain respond to non- steroidal anti-inflammatory drugs, severe pain may warrant use of opioids.[4]

3. Cough : is a distressing symptom, can significantly impact quality of life by disrupting sleep. It not only induces nausea itself but also leads to loss of appetite, resulting in weight loss. Non-pharmacological approaches include sipping water and consuming warm fluids. Additionally, educating patients about effective coughing techniques is crucial for infection control.[4] Furthermore, low-dose morphine has been recognized for its ability to suppress the cough reflex, alongside traditional anti-tussive medicines.

4.Hemoptysis : a serious complication of tuberculosis (TB), often results from bronchial artery involvement. It can occur due to various factors, including bleeding from a cavity, post-TB sequelae such as bronchiectasis or aspergilloma, or even a ruptured "Rasmussen's aneurysm". [7] Whether it presents as minor hemoptysis, a single major episode, or a potentially fatal event, it can be profoundly distressing for patients and their families. Effective management involves providing anticipatory guidance to address the bleeding and reduce panic.

5. Respiratory secretions : Increased secretions in TB can be attributed to over-production or difficulty in elimination. Pooling up of secretions can in turn increase dyspnea and cough. Hence the main goals of management revolve around promoting expectoration, increasing clearance of secretions to upper airways and improving cough effectiveness.[8] Saline nebulization can be used to loosen the mucus. Mucolytics and anticholinergics can also be used to reduce secretions.

6. Insomnia : A number of reasons can cause insomnia ranging from physical factors such as orthopnea, cough to psychosocial factors pertaining to the disease. Identifying the root cause and addressing it is imperative to the management.[9]

7. Anorexia-cachexia : TB is a hypercatabolic state characterized by accelerated protein degradation, muscle wasting causing weight loss.[10] Nutritional support plays a vital role in weight gain and facilitating early recovery.

8. Fatigue : It is determined by the nutritional status of the patient, their quality of sleep and depression.[11] Preventing and managing the above symptoms reduce the chances of developing fatigue or it effects.

9.Others : According to the site of TB, specific symptoms have to be managed. For e.g. seizure-related to TB meningitis requiring anti-epileptics.

PSYCHOLOGICAL SUPPORT :

Uncertainty of curability can cause feelings of rage, despair, grief, anxiety, and dread. Therefore, during the duration of the illness, honest communication with the precise facts pertaining to the disease and response to treatment should be shared.

It is also essential to respond to their questions and concerns. Some of the concerns expressed by patients include losing their role as a parent or breadwinner, being dependable, feeling like a burden to the family, fearing for their future financial security, feeling helpless, and fearing that they will spread the disease to other family members.

The term "tuberculosis" still carries a lot of social stigma in our society.[12] The diagnosis itself causes anxiety and has a wide range of psychological and social ramifications. The idea that it is a death sentence is false.

On the other hand, the family could want clarifications regarding infection management and duration of treatment. There is need for educating the patient and family about the necessity of adherence and compliance to avoid problems like resistance, and recognition and reporting of adverse effects which may call for modifying the dosage or regimen. Patients may experience depression due to isolation.

This is misdiagnosed because it overlaps with physical symptoms.[13]

It might be beneficial to use antidepressants in some patients. The psychological issues can be navigated by early recognition of the suffering , communicating effectively, and providing emotional and supportive counseling.

SOCIAL SUPPORT :

A TB social worker assists patients with TB and patients at risk of developing TB. As a part of the interdisciplinary team they increase the treatment compliance among these patients. They aid in linking the TB patients to healthcare centers. Financial assistance includes raising awareness of the availability of insurance or welfare schemes. The TB social worker can help by locating homeless patients, assist them with permanent lodging, and coordinating transportation to ensure patients get to their required TB appointments. During active tuberculosis patients require medical isolation which interferes with going to their jobs, which in turn results in inability to pay for home rent, utilities and food. Here a social worker can advocate to complete the necessary procedures for signing up for community agencies.(14) The involvement of patient support groups, non-governmental organizations, community or faith-based organizations can take care of the social isolation patients might face and make them feel as a part of a community.

SPIRITUAL CONCERNS :

Spirituality refers to the way an individual seeks and expresses meaning and purpose and the way they experience their connectedness to self, the moment, others, nature and the significant or sacred through beliefs, values, tradition and practices.[15] Factors influencing coping are age, hope and social support. Hope is built through trusting relationship with others which includes God. Lack of hope can lead to depression, anxiety etc. Culture and spirituality can affect the way an individual thinks. And when channeled appropriately can optimise, support and accelerate healing through realising the meaning and purpose of life. Meditation has shown to improve emotional control in TB patients. Spiritual activities coupled with physiological activities reduced stress giving patients the resilience to face the illness. High spiritual intelligence was associated with reduced anxiety levels. [16]

NUTRITIONAL SUPPORT-AN ESSENTIAL ARENA OF CARE :

Malnutrition predisposes a person to develop tuberculosis likewise it hampers recovery when not managed. Appropriate supplementation of micro and macro nutrients hence plays a crucial role in recovery.[17] This is adequately taken care of by governmental schemes yet when complex might require the help of a nutritionist to intervene to provide individualized care.

CO-MORBIDITIES-A MAJOR DECIDING FACTOR :

When determining if palliative care is necessary, patients with tuberculosis may also have additional co-morbidities. As, diabetes mellitus is a common condition in the general community, 1 in 4 persons who have tuberculosis also have diabetes.[18] Patients with diabetes have a higher risk of developing tuberculosis disease from a latent tuberculosis.

A complete cure necessitates constant monitoring and good glycemic control. Diabetes, co-morbidities such heart problems, kidney failure, and liver dysfunction add to the burden and raise the need for palliative care.

Immunosuppression can result from a variety of internal and external factors, including HIV infection, chronic kidney disease, autoimmune diseases, malnutrition, liver cirrhosis, and the use of immunosuppressants. The compromised immunity increases the risk of developing extrapulmonary sites of tuberculosis or disseminated illness.[19]

Tuberculosis is the most common opportunistic illness in people living with HIV. One of the main causes of death for HIV-positive individuals is tuberculosis. Fever is the most common symptom of an unspecific clinical appearance.

Dialyzed patients have a significant morbidity rate from TB because of immunosuppression brought on by uraemia.

END OF LIFE AND BEYOND :

End of life care is provided during a time period of hours, days or month before a person dies. The services of palliative care in end of life is important in complex symptom management. Deciding if a person should continue TB treatment during end of life is an ethical dilemma requiring a joint decision made with the person suffering from TB, family and the treating physician.[20]

Palliative care services extend beyond death of the patient. Bereavement services to families who have lost their loved ones will help them cope with the loss. Giving a good quality of death should be the aim of palliative care during end of life. As quoted by Atul Gawande in his book "Being Mortal: Medicine and what matters in the end", "Endings matter, not just for the person but perhaps even more for the ones left behind."

CHALLENGES IN PROVIDING PALLIATIVE CARE :

One big disadvantage is that not everyone is aware of palliative care. There is a misconception that PC is only limited to end-of-life. That primary care physicians, who are actively involved in a patient's treatment can offer primary palliation necessitates advocacy. The use of palliative care in infectious diseases such as tuberculosis, rabies, malaria, and other illnesses is a new area that requires development.[21] Only limited information is available about the benefits of palliative care, its guiding principles, and its use in tuberculosis. To increase palliative care engagement in tuberculosis, it is necessary to empower primary healthcare providers and identify trigger tools for the integration of specialist palliative care provider. There are but a few medical practitioners with palliative care training. Despite receiving training in palliative care, understanding the application of tuberculosis necessitates specific knowledge and skills in the disease. The provision of community-based palliative care at the primary health care center level, and teaching pulmonologists and respiratory medicine specialists to provide primary palliative care, will help close this gap and promote patient care as a holistic undertaking. Due to the complexity of procuring, storing and dispensing opioids there is problem in accessing them in TB facilities for pain and dyspnea. Utilization when available is also less due to unfamiliarity of the indication for use, fear of respiratory depression, weaning when not required and possibility of dependence, addiction and drug seeking behavior.

CONCLUSION

Palliative care in tuberculosis is underexplored and this article introduces the scope of PC in tuberculosis. It describes the potential benefits of a palliative care approach provided through a multidisciplinary team for a patient and family suffering from TB.

RECOMMENDATIONS

Capacity building in PC for tuberculosis has to be undertaken by conducting training programs for healthcare professionals in TB centres in a time bound manner. Creating awareness among providers to extend PC even to drug susceptible patients is imperative. Also, of importance is developing a trigger tool for specialized palliative care referral. Experts in both fields can work together in designing a consensus document about PC in tuberculosis for guiding primary physicians. Further research to understand patient experiences and identify specific palliative care needs of patients with TB across various domains must be carried out. Creating awareness among providers to extend PC even to drug susceptible patients is imperative. Also, of importance is developing a trigger tool for specialized palliative care referral.

REFERENCES

1. World Health Organisation. National cancer control programmes: policies and managerial guidelines. 2nd ed. Geneva: World Health Organization; 2002.

2. Palliative Care By World Health Organisation Year: 2020 Container: World Health Organization Publisher: World Health Organization[Published 5 Aug 2020 Available from https://www.who.int/newsroom/factsheets/detail/palliative-care]

3. Uplekar M, Weil D, Lonnroth K, Jaramillo E, Lienhardt C, Dias HM, et al. WHO's new end TB strategy. Lancet. 2015;385(9979):1799-801.

4. Rai DK, Sharma P. Palliative Care in Drug Resistance Tuberculosis: An Overlooked Component in Management. Indian J Palliat Care. 2023;29(4):388-93.

5. Guidelines for programmatic management of drug resistant tuberculosis in India. 2021 [Available from: https://tbcindia.gov.in/showfile.php?lid=3590].

6. Parshall MB, Schwartzstein RM, Adams L, Banzett RB, Manning HL, Bourbeau J, Calverley PM, Gift AG, Harver A, Lareau SC, Mahler DA. An official American Thoracic Society statement: update on the mechanisms, assessment, and management of dyspnea. American journal of respiratory and critical care medicine. 2012 Feb 15;185(4):435-52.

7. Vaishnav B, Bamanikar A, Rathore VS, Khemka VK. Fatal hemoptysis due to ruptured peripheral pulmonary artery pseudoaneurysm. Lung India. 2017;34(1):106-7.

8. Arcuri JF, Abarshi E, Preston NJ, Brine J, Pires Di Lorenzo VA. Benefits of interventions for respiratory secretion management in adult palliative care patients—a systematic review. BMC Palliative Care. 2016 Dec;15:1-1.

9. Renom-Guiteras A, Planas J, Farriols C, Mojal S, Miralles R, Silvent MA, Ruiz-Ripoll AI. Insomnia among patients with advanced disease during admission in a Palliative Care

Unit: a prospective observational study on its frequency and association with psychological, physical and environmental factors. BMC palliative care. 2014 Dec;13:1-2.

10. Zheng Y, Ma A, Wang Q, Han X, Cai J, Schouten EG, et al. Relation of leptin, ghrelin and inflammatory cytokines with body mass index in pulmonary tuberculosis patients with and without type 2 diabetes mellitus. PLoS One. 2013;8(11):e80122.

11. Thedthong W, Puwarawuttipanich W, Saneha C, Rongrunguang Y. Factors Predicting Fatigue in Pulmonary Tuberculosis Patients Receiving Anti-Tuberculosis Drugs. Southern Medical Journal. 2021;73:167-73.

12. Emami H, Modarressi T, Najmi K, Radmand G, Monjazebi F, Tabarsi P, Richter J. Psychological symptoms before and after a 14-day initial inpatient treatment in tuberculosis patients compared with their primary caregivers and healthy controls. Tanaffos. 2015;14(3):182.

13. Duko B, Bedaso A, Ayano G. The prevalence of depression among patients with tuberculosis: a systematic review and meta-analysis. Annals of general psychiatry. 2020 Dec;19:1-1.

14. Sandesh KS, SV S, Baliga K, OR R. The essential role of social work in the treatment of tuberculosis. Global Journal for Research Analysis.2020:1-3.

15. Ghaderi A, Tabatabaei SM, Nedjat S, Javadi M, Larijani B. Explanatory definition of the concept of spiritual health: a qualitative study in Iran. Journal of medical ethics and history of medicine. 2018;11.

16. Widyastuti M, Hastuti P, Kirana S, Farendita N. The Correlation of Spiritual Status and Anxiety Level in Patients with Pulmonary Tuberculosis. Jurnal Ners. 2020;15:67-71.

17. Gupta KB, Gupta R, Atreja A, Verma M, Vishvkarma S. Tuberculosis and nutrition. Lung India. 2009 Jan 1;26(1):9-16.

18. TB and Diabetes [updated October 26 2023. Available from: https://www.cdc.gov/tb/topic/basics/tb-and-diabetes.html.

19. Guedes G. Tuberculosis and immunosuppression. Journal of Microbiology & Experimentation. 2018;6.

20. World Health Organization. Companion Handbook to the WHO Guidelines for the Programmatic Management of Drug-Resistant Tuberculosis. Geneva: World Health Organisation; 2014.

21. Bruera E, Higginson, I.J., von Gunten, C.F., & Morita, T. Textbook of Palliative Medicine and Supportive Care 3rd ed ed: CRC Press; 2021. 974 p.