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Review Article

Palliative care: Time for action

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ABSTRACT

Palliative care improves the life quality of client and also for their families who are suffering with challenges associated with life-threatening illness, whether physical, psychological, social or spiritual. The quality of caregiver's life also improves.

According to WHO each year, an estimated 40 million people are in need of palliative care; 78% of them people live in low- and middle-income countries. Worldwide, only about 14% of people who need palliative care currently receive it. Unnecessarily restrictive regulations for morphine and other essential controlled palliative medicines deny access to adequate palliative care.

1. Introduction

Cancer is a generic term that can be defined as a group of diseases which involves a rapid creation of abnormal cells which have the potential to invade the adjoining parts of the body. Cancer cells does not follow a uniform life cycle or reproduction, these cells follow an abnormal path and reproduce, grow erratically and lead to the transformation of normal cells into abnormal or mutant cells, that eventually progress to form a malignant tumor. All these changes are because of the interaction of many factors together that may be either genetic, environmental or constitutional related to the individual.

The incidence of cancer is rising dramatically, ranking as a leading cause of deaths worldwide. An WHO estimated figure of about 10 million deaths were recorded in the year 2020. In Asia, 58.3% of cancer deaths were recorded in the year 2020 by WHO estimates for both sexes. Over viewing the burden of cancer incidence, the incidence and mortality rates are rapidly growing worldwide.[1]

About 30-50% of cancers can be prevented by avoidance of the risk factors and also by implementing the evidence based preventive strategies. Cancer mortality rates can be reduced by early diagnosis and screening as well.[1]

Cancer is considered as one of the dangerous diseases by ones who on the forefront of such disease as it follows a trend of being diagnosed at a stage where the disease has already progressed to a more severe stages and thus recovery seems likely impossible. However, whatever the stage, the treatment is multifold and involves different strategies to combat the illness. As far as the treatment goes, Chemotherapy, Radiotherapy, Surgery, etc. are mostly known to general population. Whereby, chemotherapy involves a regime of different drugs given to either cure, limit side effects, radiotherapy means use of different wavelength of radiations to kill the cancerous cells threatening to invade adjacent normal cells.

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With all the talk about different treatment regimes, there are a number of other treatment modalities that are yet not known to general population due to many reasons or are not made available to general population and thus common people are deprived of such facilities. Of such facilities/ treatment modalities, palliative has proven to be one of the effective strategies to atleast rehabilitate as far as serious illnesses are concerned, one of which being Cancer.

"A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity".[2]
— *WHO Constitution*

Palliative Care is a specialized care being provided to the patients associated with the life-threatening illness be it related to physical, psychological, social or spiritual dimension. Palliative care is an essential approach to provide comprehensive care which aims to improve the quality of life of not only of patients, but also takes the health of family members of the patient into account. Palliative Care is peculiarly the basic right of an individual to health. It should be provided through integrated services that can eventually reduce the unnecessary hospital admissions. Yearly, about 40 million people are estimated to be in need of palliative care including 78% population from low and middle economic countries and only about 14% of the population who need access to palliative care, receive it. According to WHO survey relating to non-communicable diseases, conducted among 194 member states in 2019 funding for palliative care was available in 68% of countries and only 40% of countries reported that the services revealed at least half of patients are in need.

2. What Does Palliative Care Bring On to The Table For Us?

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

Addressing suffering involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling. It offers a support system to help patients live as actively as possible until death.

Palliative care is explicitly recognized under the human right to health. It should be provided through person-centered and integrated health services that pay special attention to the specific needs and preferences of individuals.

Palliative care is required for a wide range of diseases. The majority of adults in need of palliative care have chronic diseases such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%). Many other conditions may require palliative care, including kidney failure, chronic liver disease, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies and drug-resistant tuberculosis.

Pain and difficulty in breathing are two of the most frequent and serious symptoms experienced by patients in need of palliative care. For example, 80% of patients with AIDS or cancer, and 67% of patients with cardiovascular disease or chronic obstructive pulmonary disease will experience moderate to severe pain at the end of their lives. Opioids are essential for managing pain.

Opioids can also alleviate other common distressing physical symptoms including breathlessness. Controlling such symptoms at an early stage is an ethical duty to relieve suffering and to respect a person's dignity.[1]

Despite many advances in understanding the early benefits of implementing palliative care, people living with life limiting diseases either do not receive any palliative care services or receive only at the later phase of their illness. There are many reasons for the failure to provide palliative care services like as:

1. Lack of resources to refer to
2. Not knowing that resources exist
3. Ignorance regarding what palliative care is
4. Reluctance to refer
5. Reluctance of patient and or family to be referred
6. Restrictive specialist palliative care service program eligibility criteria.

2.1. What are some possible spanners in the work?

1. Lack of awareness among policy-makers, health professionals and the public about what palliative care is, and the benefits it can offer patients and health systems;
2. Cultural and social barriers, such as beliefs about death and dying;
3. Misconceptions about palliative care, such as that it is only for patients with cancer, or for the last weeks of life;
4. Misconceptions that improving access to opioid analgesia will lead to increased substance abuse.
5. Political debacles**.**

3. Palliative Care and Jammu and Kashmir

Jammu and Kashmir is located in Himalayan region in the north of India. Jammu and Kashmir population in 2022 is estimated to be 14 Million (1.4 Crores), According to Unique Identification Aadhar India, updated 31 Dec 2020, by mid of year 2020 the projected population is 13,606,320. For such huge numbers, we only have two pain and palliative care centers, I.e. Hakim Sanaullah Cancer

Centre Mazbugh Road, Sopore and Pain & Palliative Care Centre Sher-I — Kashmir Institute of Medical Sciences Soura, Srinagar as reported by the stats of Indian association of palliative care. Imagine the case scenarios across a 14 million population region and with geographical, political and Environmental debacles taken into consideration, the numbers are going to be lot worse than imagined.

The need of the hour raises alarm bells, suggesting setting up of more such center's especially in tertiary areas where road and air connectivity is a major hurdle and economy being another.

3.1. Palliative care and Covid-19 pandemic

A disaster situation such as the COVID-19 crisis highlights the specific challenges faced by patients and their caregivers on palliative care. An analysis of 95 peer-reviewed and gray literature documents reveal a scarcity of data on palliative care needs and interventions provided in crises, challenges of care provision, particularly due to inadequate pain relief resources and guidelines, a lack of consensuses on the ethics of providing or limiting palliative care as part of humanitarian healthcare response, and the importance of contextually appropriate care.[3–5]

Prajakta Dhavale, Akhila Koparkar, Prakash Fernandes, Department of Social Work, Cipla Palliative Care and Training Centre, Warje, Pune, 1 Department of Palliative Care Partnerships, Cipla Foundation, Mumbai, Maharashtra, India, (August 4, 2020), did an exploratory study on "Palliative Care Interventions from a Social Work Perspective and the Challenges Faced by Patients and Caregivers during COVID-19". The aim of the study was to describe the range of challenges faced by both patients and caregivers during the lock down due to the COVID-19 pandemic. It also seeks to describe the nature of interventions provided by the social work team to address these challenges. This exploratory study used a qualitative approach and analyzed the perceptions of patients, their caregivers, and the staff in providing care. Out of 30 patients worked with during the lock down period, a total of nine families were selected that had received services during this time. The challenges faced and the interventions provided were analyzed using Framework analysis. The Results of the study showed that the range of challenges faced by patients included physical distress due lack of availability of medicines and nursing care; emotional distress due to the interruption of cancer treatment; financial and social distress about loss of incomes, isolation; and spiritual distress due to the uncertainty of last rites as well as fulfillment of last wishes. The concerns outlined by caregivers included: living with guilt due to the inability to ease their relative's distress; the stress of constant care giving; lack of information about available services and confidence to ask for help from others as well as the dealing with the grief of a dying relative. These families were supported through telephone calls and home visits for critical patients with the social work team providing active listening, reassurance, empathy, and networking to assist patients and families at this time. The Conclusion of the study was that the Palliative care is an essential component, especially in a disaster-related situation such as the COVID pandemic as patients and caregivers are left more vulnerable at this time. Telephonic and video calls play an important role in supporting patients and caregivers and in the most critical cases. However, it is also important to find the ways to provide direct home-based support to patients and families at this time so that they feel less alone, cope better, and experience meaningful support to build their resilience. Therefore, it leads to an immense need for palliative care especially in this modern era as despite all the medical advances, patients associated with life threatening illnesses abide remarkably.[6]

WHO recognized palliative care as an essential part of the universal health coverage so as to deal with the changing patterns of disease especially for ageing population with chronic diseases. Palliative care has been one of the main public health issue as it has been one of the most neglected areas of medicine. So, there is dire need for the development and implementation of palliative care services to be applicable throughout the course of illness as it focuses in almost all the disciplines and dimensions related to patient's health care. One of the burdens of the patients diagnosed with cancer is usually the cost related to the treatment of the disease and few organizations like CIPLA palliative care center in India provides this care aspect for free around 40km radius in major cities of India. So, it almost covers all the dimensions of health as stated by World Health Organization (WHO) and thus stresses on the importance of having facilities of palliation in different parts of world.[7–9]

"We cannot change the outcome, but we can affect the journey" –*Ann Richardson.*[10]

4. Source of Funding

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5. Conflict of Interest

The author declares that there is no conflict of interest.

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