

A Review on Palliative Care Challenges and Benefits

AMIT AGRAWAL¹, DALWINDER JANJUA², ROSHAN CHANCHLANI³, ALEJANDRO PANDO⁴



ABSTRACT

Palliative care is a treatment strategy that aims to improve the quality of life of patients suffering from various serious illnesses. Palliative care is provided to these patients by experts from multidisciplinary fields utilising a holistic approach. It reduces the burden on families and patients by providing services related to pain management, early diagnosis and assessment, and by addressing their psychological, spiritual, ethical, and cultural issues. The aim of this narrative review is to cast light on the cost-effectiveness, evolution, and challenges of palliative care. Databases including Medline/PubMed and Google Scholar were searched to retrieve relevant studies including clinical trials, case studies, and meta-analyses and reviews. Information obtained from these studies includes cost-effectiveness, palliative care evolution, and palliative care-related social issues among patients and family members as well as healthcare professionals. The purpose of this narrative review is to summarise the barriers and recent advancements of palliative care in terminally ill patient care.

Keywords: Hospices, Hospice care, Patient care, Terminal care

INTRODUCTION

The World Health Organization (WHO) defines Palliative care as “an approach that improves the quality of life of patients and that of their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social or spiritual”. Palliative care is recognised as the basic health right of an individual [1]. It takes a multipronged approach centered around the healthcare team, the patient and the patient’s family, while the patient advances from a deteriorating health condition to the last hours of his or her life [2]. It is estimated that approximately 40 million people require palliative care each year, but worldwide only 14% receive this care [3].

Principles of palliative care are influenced by key areas such as type of service models adopted, care co-ordination among healthcare professionals, education and training for non hospital staff, equality to access for all patients, communication between healthcare professionals, patients and family at every stage, and responding to the specific needs of the patient and family [4]. Palliative care has taken various forms since its genesis, and has progressed at a different pace in nations around the world.

In accordance with the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines 2018, palliative care seeks to address the following domains: structure and processes of care, physical, psychological, psychiatric, spiritual, religious, cultural, legal, ethical and existential aspects of the patient care, clinical implications and the holistic care of terminally-ill patients. Palliative care can begin in a local hospital, emergency room, community house, or residential setting. In diseases like cancer, clinicians generally advocate palliative care in the very early stages once the diagnosis has been established [5]. According to a report, the demand for palliative care is expected to rise globally over the next 10 to 20 years due to changing demographics, emergence of chronic diseases, and high morbidity rates. Addressing pain demands going beyond the physical dilemmas, and in this review, we have summarised the cultural and ethical barriers to effective palliative care delivery.

Although palliative care has been recommended by worldwide accepted medical policies and frameworks, grant allocation for palliative care research has historically been significantly inadequate [6]. For example, in 2013, the National Cancer Research Institute in the United Kingdom allocated 0.61% of its yearly research budget

to palliative and End Of Life (EOL) care [7]. Cost effectiveness is yet another challenge on the way to achieve quality palliative care services. According to the Global Atlas of palliative care, a large proportion of adult patients requiring palliative care suffer from cardiovascular diseases (38.5%), followed by cancer (34%), obstructive respiratory disease (10.3%), Human Immunodeficiency virus/Acquired Immuno-deficiency syndrome (HIV/AIDS) (5.7%) and diabetes (4.5%) [8]. Cross culture competence among healthcare professionals and understanding of the various practice around the world can be a useful tool. For patients with a prognosis of six months or less, hospice care can be the healthcare strategy as it is similar to palliative care, when the goal is to avoid hospitalisation and to maximise time spent at home for patients nearing the end of their lives [9].

Unmet need of palliative care is an insurmountable issue. Increasing awareness among the health professionals, national policy makers and patients can ensure continuum of care for people with chronic and life-threatening diseases. In this review, authors aim to summarise the evolution of palliative care, its cost-effective profile, the barriers involving cultural and ethical issues. The review also sheds light on the issues surrounding implementation of palliative care in the rural settings. Finally, the review gives a brief summary on the status of do not resuscitate across nations around the world.

LITERATURE SEARCH STRATEGY

A literature search was performed using databases Medline/PubMed, and Google Scholar to retrieve the relevant studies including clinical trials, case studies, and meta-analyses and reviews. Information obtained from these studies includes cost-effectiveness, palliative care evolution, and palliative care-related social issues among patients and family members as well as healthcare professionals. The following combinations of keywords were used: palliative care and end-of-life care, evolution and progress in palliative care in the emergency departments, the cost-effectiveness of palliative care, challenges of palliative care in rural areas, and ethical, cultural, and spiritual issues in palliative care. The search was restricted to papers published in English.

EVOLUTION OF PALLIATIVE CARE

Evolution of palliative care in the United States (US) took place gradually with the development of innovative delivery models and

resultant increase in demand for palliative care [10]. Policy makers, health advocacy, public education, and philanthropic commitment are the primary drivers for the rooting of palliative care in the US. In comparison to the number of patients receiving community based palliative care, patients admitted to the hospital for palliative care are increasing since 2000 [11]. According to a status report on palliative care, there has been steady growth with nearly universal access to public healthcare services in large US hospitals and medical institutions [10]. Nonetheless, access to palliative care is still unequal and is influenced by geographical location and on the varying hospital facilities (number of beds, staff, etc.). Almost two-thirds of all hospitals in the US offer palliative care. Palliative care programmes were available in 90% of hospitals with 300 beds or more, compared to 56% of hospitals with fewer than 300 beds. Similarly, 67% of hospitals with 50 or more total facility beds reported having a palliative care programme. However, there are significant differences in palliative care policies and guidelines around the world, reflecting the huge discrepancy in pain medication access [11]. Other barriers to palliative care implementation in developing and underdeveloped countries include a lack of exposure to palliative care content in medical curricula and misunderstanding with respect to its implementation (e.g. access to opioid analgesia will increase substance abuse) [12,13].

In addition, there is a common misconception that palliative care can only be accessed by cancer patients or those nearing the end of their lives. Recognising that patients with chronic diseases experiencing pain, as well as other symptoms that are inadequately managed, has highlighted the importance of palliative care in both high and low resource settings [14]. It has been observed that there is improvement in the quality of life among veterans following the implementation of a series of transformative healthcare structures, appreciation of the change in institutional culture, and better initiative by the Department of Veterans Affairs (VA). The VA's strategic top-down and bottom-up approach to developing programs, policy proposals, and initiatives gives vital points of view and merits consideration in the broader US healthcare system [15]. These efforts have paid off; studies show that the addition of palliative care in hospital facilities improves health satisfaction and family satisfaction, saves money, and reduces resource utilisation.

It is predicted that by 2060, there will be a global increase of at least 87% in the serious illnesses appealing to palliative care interventions [13]. According to the 2015 survey report, 37% of the countries had an operational national policy for Non Communicable Diseases (NCDs) that included palliative care. Palliative care services were financially disadvantaged when compared to other NCDs services and a large country-income gradient existed for palliative care funding, oral morphine availability, and palliative care integration at the primary levels of the health system [16]. According to a 2017 World Health Organization (WHO) survey, 68% of countries have palliative care grants, and roughly one-third of countries reported that palliative care was generally provided by the primary healthcare facilities (35%) and community or home-based care (37%) [17]. Countries in the Global North, accounting for 41% of the world's population, have a high level of development in the palliative care services and while low-and middle-income countries account for 80% of the need for palliative care. Total 53.3% of the world's population resides in the countries with very limited palliative care facilities; mainly in the Global South, though not exclusively. The rest (4-8%) is located in countries that have no known palliative care activity or building their set-ups, and in territories that were excluded in the survey (0-1%) [13].

COST-EFFECTIVENESS OF PALLIATIVE CARE

The cost-effectiveness of palliative care is well-documented in financially developed economies, and the favourable cost profile is always a powerful motivator to increase the supply of palliative care

services in high-income societies. The percent of money saved at the hospital when palliative care is implemented ranges from 9% to 32% [18,19]. Studies have also elaborated on the monetary benefits for the healthcare system with the active implementation of palliative care [18-20]. For patients discharged early and for patients whose death happened during the hospital stay, the savings the hospital could have had were \$4098 and \$7563, respectively [20]. Cost analysis of the deaths that have occurred in the hospital have shown that when palliative care was instituted there was a 40% reduction in admission to the Intensive Care Units (ICUs) [21]. On the contrary, in low and middle-income countries, there is lack of documentation on the cost-effectiveness of palliative care and it is a critical socioeconomic barrier to the availability of palliative care [22]. Currently, the financial costs of incurable diseases are incompletely defined in low and middle-income countries, as well as in unstructured healthcare systems [23].

Furthermore, information about the cost-effectiveness of palliative care is an important factor to decide the financial expenditure of palliative care in low-income and middle-income nations, which will help in guiding health policy and endorse sustainable development. There are two approaches to compare the costs and outcomes of different interventions to direct public healthcare policy decisions at the population level: Cost-Effectiveness Analysis (CEAs) and Cost-Benefit Analysis (CBAs). CBAs aid in the conversion of impact into cost expenditure, whereas CEAs use health adaptation units to obtain a specific amount of output, such as Quality-Adjusted-Life-Years (QALYs), which measures the overall burden of disease [24]. The CEA approach is widely used in global health policy to reduce the cost of high-quality medical care. As the prevalence of NCDs, HIV/AIDS, and cancer cases continues to rise in low and middle-income countries, CEA has proven to be a valuable and effective tool in developing models for implementing high-quality healthcare systems. In high-incidence settings, active case seeking in the community; particularly in rural areas with limited healthcare facilities, can considerably enhance diagnostic and treatment coverage [25]. Examples include community-based HIV and tuberculosis screening with connection to care, *Mycobacterium tuberculosis* culture for HIV-infected individuals, cancer prevention and treatment, and lung cancer treatment.

The monetary burden of any disease has increased in high-economic countries for both patients and the community. Factual work and a cost-avoidance economic model have aided in determining the cost-effectiveness of palliative care. As a result, the provision of palliative care in high-income countries has increased in the last few decades for monetary reasons while also enriching the quality of life. There is still significant inconsistency on how services are provided to patients in terms of palliative care setting, team member composition, treatment options, and physician consultation [23,26]. In the absence of palliative care in low-and middle-income countries, uncontrolled pain and psychological sequelae for the sufferer and caregivers are common in the case of incurable disease and life end timing. Furthermore, personal and societal costs mount, sometimes insurmountably [27]. These costs include not only direct expenses associated with illness, such as the cost of treatments and medication but also indirect and frequently hidden costs associated with illness.

Health economics is slowly making inroads as an integral part of the pedagogy and practice of palliative care, despite being an evolving concept. It is crucial to know the financial burden to the individuals as well as communities when faced with an ever-growing number of investigations for consultation and follow-up. It also includes travel expenses, job loss for patients and caregivers, and the sale of personal valuable assets such as a gold ornaments or a family home [28,29]. Furthermore, the sale of land and livestock, as well as unmanageable school fees for children, serve to reduce a family's future earning potential while dealing with the burden of illnesses.

Ghoshal A et al., investigated the effectiveness and cost-effectiveness of home-based palliative care and discovered that they help reduce disease symptoms and increase the likelihood of dying at home rather than in a hospital (28). While admitting that more research into cost-effectiveness is needed, the authors concluded that their findings justify providing home-based palliative care for those who wish to die at home. Smith S et al., examined the costs and cost-effectiveness of palliative care and discovered that it was consistently less expensive than the alternative options [29].

CHALLENGES WITH PALLIATIVE CARE

Cultural Issues

Palliative care in a diverse society, both ethnically and culturally, require understanding from healthcare providers to respect and consider the specific cultures of their patients. Health professionals who learn about culture and ethnicity through dedication and knowledge are able to better manage their patients' pain. They can assist families and patients in adjusting to the dying process. Understanding the patients' and their families' beliefs, experiences, and values improve the quality of patient care. Before reaching patients with a prognosis, healthcare providers should also understand the family's and patients' faith and religious beliefs [30]. Religion and spirituality play a significant role in patients' healthcare decisions; although, many health professionals overlook this factor or the functional impact it may have on the assessment and treatment of suffering and palliative care [31].

Dame Cecily Saunders founded the hospice care movement and recognised that unresolved emotional and spiritual issues exacerbate the agony of dying. Spirituality is an essential component of suffering and addressing spiritual care during palliative care is significant for the relief of pain and suffering in such patients [32]. She referred to this as spiritual pain and claimed that it stemmed from a "desolate feeling of meaninglessness." Finding meaning in one's suffering is thus a healthy process that can help one cope with pain and other unpleasant symptoms.

Dying patients frequently wonder, "Was my life worthwhile?" "Did I make a difference?". Different communities and societies have different cultural beliefs about the origin and role of pain, which influences patients' reactions to their pain [33]. Opioids, which are commonly used to alleviate pain, are not widely accepted or encouraged in many cultures. This is a difficult barrier to overcome because opioids are a common pharmacologic treatment for those in severe pain near the end of their lives. Alternative techniques that can be used in conjunction with opioids, such as herbs, cupping, moxibustion, and coining, must be known to health practitioners. In some cases, patients request that a spiritual healer use medicinal herbs in their treatment [34].

Ethical Issues

There are numerous ethical issues to consider when providing palliative care to patients nearing the end of their lives. By using their knowledge and skill, Primary Care Providers (PCPs) should identify ethical issues to avoid future conflicts, as well as assist patients in making medical decisions that take into account the patient's values and preferences [35]. The goal of medical ethics is to provide guidelines and codes for physicians regarding their duty, responsibility, and conduct, as well as common principles that overlap with other ethics, such as nursing ethics and bioethics. The main ethical principle for palliative care is respect for autonomy, non maleficence (the duty not to harm), and justice [36].

Respect for autonomy is defined as the patient's independence in making treatment and disease management decisions. Patients who are terminally ill will make decisions about their care and plan for the future. Patients, on the other hand, lack the autonomy to direct a health provider to give a lethal injection [37]. Furthermore, case law

establishes that a patient may not demand treatment that a physician deems to be inconvenient or not in the patient's best interests. The physician, in consultation with the patient or caregivers, still makes the decision to treat. A competent patient has a right to refuse therapy despite knowing that doing so may result in the patient's death. If a patient requests a lethal treatment, other ethical principles, such as non maleficence, will be violated [38].

Non maleficence- as per the principle, it should always be remembered that there are a variety of therapy courses that may have unintended side effects but may ultimately improve one's life [39]. As a result, the scope of the 'harm' or burden must be defined, as must the concept of whether death is an acceptable 'harm'. This duty states that any action taken by a healthcare worker should always result in a net benefit to the patient's quality of life. The burden of treatment is not always easy to anticipate and if a treatment is extremely strenuous, it may not be in the individual interest to continue.

Justice is defined as the equitable and fair distribution of resources. It is especially important in cases where patients cannot afford expensive treatments [40].

The application of ethical principles may aid in balancing competing interests. Collusion is a very common practice in cancer cases, where family members ask for favorable treatment that keeps the truth away from patients. Although it is extremely difficult in today's scientific environment, concealing disease information from the patient was an acceptable norm until the last half-century [41]. Over the time, the increase in patient autonomy in well-educated public, has changed the traditional practices in the western countries, and the open disclosure norm is now more popular [42]. Still, many institutions continue to take a cautious approach, and it is not uncommon for family members to be informed before the patient.

The main factors involved in the patient-doctor relationship are respect to the patient's self-determination and autonomy heritage [43]. Although it is meant to protect the patient's interests, it can be a cause of distress and disagreement in the ethical quandaries. Moral distress is the term used to describe stress caused by ethical quandaries. It refers to a moral agent's inability to act in accordance with his own core values and perceived obligations as a result of internal and external constraints [44]. In some countries; especially, the Middle East countries, religious and cultural practices have an important influence on the final decision made by the healthcare practitioner [45,46].

Recent study showed that at least one third of the family caregivers face personal and emotional pressure and burden of decision with doubt and guilt which can be a possible cause of depression, grief and unhappiness. Family caregiver burden was reported in terms of decision-making burdens, lack of certainty about the patients' last wishes and values, and differing desires for the place of death. Withholding and withdrawing treatment, pain medication use, clear communication of disease and treatment, hydration, and nutrition are all stressful and difficult ethical issues in family care [47]. A survey conducted in the Norwegian nursing homes describes the unavoidable presence of ethical issues while making EOL decisions. It was observed that ensuring patient autonomy and integrity without any breach in the freedom of patient to choose about the EOL decision are common ethical dilemmas in most of the nursing homes [48].

Issues in the Rural setting

Rural communities are interconnected networks of social solidarity, commitment, and networks [49]. Although rural areas are advantageous in many ways such as local support networks, access to quality EOL care becomes difficult due to limited availability of healthcare services. Rural palliative care is essentially a primary care only, with limited access to multidisciplinary specialist palliative care services [50].

Most rural residents prefer to die at home; however, if this is not possible, nearby hospitals and aged home care are considered as alternatives. The universal rural theme is that if rural residents are unable to die at home, they must die in their community. Guidelines and working models for implementing palliative care in rural areas are severely limited. The majority of models are implemented in urban tertiary hospitals by teams of trained clinicians and healthcare workers from a variety of disciplines [51]. Because patient volumes in urban areas are large enough to allow a team to focus on palliative medicine and have a greater proclivity to support hospital and community-based palliative care programs than in rural areas. According to previous literature, community-based palliative care programs are also very good and assist individuals in lowering costs and minimizing hospital utilisation [52]. They also provide healthcare services almost anywhere patients go, such as clinics, homes, and nursing homes.

A community-based model of palliative care in rural areas allows health workers to better understand patients' needs across the care continuum and can help align services to address clinical and non clinical needs through collaboration with an array of organisations. Community capacity-based planning, co-ordination among healthcare settings and community services, and clinical skill development through workforce training are three critical processes for meeting palliative care requirements in rural communities [53]. Many unique challenges exist in rural settings in receiving quality EOL care such as distance, traveling, access to home-based services, lack of local specialists or experts, and lack of allied health support.

Patients in rural areas must travel for treatment, diagnosis, and follow-up, which can be stressful, expensive, uncomfortable, and exhausting at times, and dangerous and difficult at others due to weather or a poor road system [54]. Family caregivers must take time off from work to visit the patient, and travel to distant hospitals [55]. These issues always cause a quandary in caregivers' decisions about whether to seek medical care locally or in a more distant location where experts and facilities are available. Access to in-home healthcare and support remains a major hurdle, due to seasonal barriers and lack of digital services in remote locations.

Access to allied healthcare services is also limited in rural areas. The availability of physiotherapy, counsellors, home nursing facilities, and social work varies by location and population [56]. While some facilities are available in rural areas, they are frequently limited to hospitalisation at a local hospital or the cost of a private fee. Community pharmacists play an important role however, they are not available very frequently in all rural areas. The various barriers to palliative care have been depicted in the image. The three main issues are cultural, ethical and the implementation of palliative care to the rural settings [Table/Fig-1].

Cultural issues	Patients's faith and religious beliefs, spirituality, ethnicity and beliefs about opioid use
Ethical Issues	Moral distress, collusion, cautious approach, nonmaleficence, autonomy and justice
Issues in rural setting	Long distance, access to home-based service, lack of local specialist or experts, and allied health support

[Table/Fig-1]: Issues in palliative care.

STATUS OF DO NOT RESUSCITATE (DNR) ORDERS IN DIFFERENT COUNTRIES

A DNR order was a commonly used term in ICUs and is getting obsolete in current era as it may give misimpression to the patients and family that the attempt to resuscitation is likely to succeed. Do Not Attempt to Resuscitate (DNAR) clearly indicates that an attempt to resuscitate the patient should not be made where it is unlikely to be

of any benefit. Allow Natural Death (AND) is another term which clearly affirms that the patient wants to follow a natural course of the disease to death and it is commonly employed in hospice patient alliance hospitals. Life Extending Treatments (LET) are usually employed in ICU in any critically ill patients; however, it might not be very useful in a palliative care setting. Here, LET can be limited by withholding future therapy or by withdrawing the current therapy while the aim is to provide consistent care to the dying patients [57-59].

The status of palliative care practices and EOL decisions vary from one country to another and it is influenced by various factors. In the US, limitation of life therapy that covers withholding and withdrawal of life support is a predominant practice in the ICUs (60). In contrast, DNR orders and withholding of life sustaining therapies are not commonly practiced norms in Brazil due to the lack of specific legislation and clinical guidelines [61]. A prospective study conducted in Hong Kong has reflected that withholding of therapy compared to withdrawal of therapy occurred more frequently in the Asian population than in the Western populations [62]. Religion, culture, family, and a physician's educational background may all have an influence on patient decisions in Middle Eastern countries. Based on their age and ethnicity, patient attributes have a higher influence on LET and AND decisions [45,63,64].

In Korea, LET is recommended when death is obvious consequently this poses a time constraint on the family, care takers and the health professionals for taking an EOL decision [65]. Slower EOL judgments were linked to longer ICU stays, implying that EOL patients require a faster, more immediate decision. The first law 'the Leonetti law' concerning the rights of patients at the EOL was proposed in April 2005 which allows the 'limitation or discontinuation of treatment and sedation for a symptom that has remained refractory until death'. On February 2, 2016, the French government enacted the Claeys-Leonetti law introducing the right to deep and continuous sedation and forbade euthanasia for end-of-life patients [66].

A lack of national health policy in most countries supporting palliative care is also a barrier to the development of palliative care and status of palliative care varies greatly amongst different countries under international law, the majority of nations such as Mexico, has adopted legislation that is concordant with stipulations in the Universal Declaration of Human Rights [67]. In the US, the development of palliative care services has been largely influenced by the fee-for-service system. The two primary models of palliative care that exist within hospitals are interdisciplinary consultation teams and inpatient units [68]. Palliative care services are being expanded in developing countries but are still in their infancy in many countries like Indonesia, Pakistan and Nigeria [69-71]. According to Yin Z et al., access to palliative care is extremely limited in China and the major barriers were lack of training opportunities, stigma on death and dying, and lack of resources and policies to support clinical practice [72]. Palliative care has been present in India for more than 20 years; however, there is lack of uniformity in the practices and availability is limited to some centers only [73]. There is significant inconsistency in how services are provided to patients in terms of palliative care setting, team member composition, treatment options, and physician consultation [30,32]. Furthermore, it has been discovered that providing education regarding use and benefits of these services can increase the use of palliative care in a culturally diverse population [74]. Many general practitioners believe that cultural beliefs are as important as pain and symptom control in palliative care, but they lack confidence in managing cultural, spiritual, and ethical issues. There is a need for specially trained general practitioners in palliative care [30,31].

CONCLUSION(S)

Palliative care encompasses treatment of the underlying disease along with pain management in EOL. Palliative care has undergone

significant changes, with varying improvements among countries across the world. Although, the developed nations have made huge leaps forward, barriers to effective palliative care in the low-and middle-income countries remain unanswered. A well-designed cost effectiveness profile of palliative care can drive its implementation across nations. Cultural issues, spiritual needs of patient and ethical intricacies impede the progress of palliative care services. Structured training in palliative care, knowledge of the local problems, and good communication skills among healthcare providers can aid to address these issues.

REFERENCES

- [1] Who.int. WHO | WHO Definition of Palliative Care. Available at: <http://www.Who.Int/Cancer/Palliative/Definition/En/>. 2012.
- [2] Shinde T, Damani A, Ghoshal A, Muckaden MA, Deodhar J. Role of respite palliative care in understanding and managing complex palliative care situation -A case report. *Indian J Palliat Care*. 2022;28(1):120-23.
- [3] Sepúlveda C, Marín A, Yoshida T, Ullrich A. Palliative care: The world health organization's global perspective. *J Pain Symptom Manage*. 2002;24(2):91-96.
- [4] Hasson F, Nicholson E, Muldrew D, Bamidele O, Payne S, McIlfratrick S. International palliative care research priorities: A systematic review. *BMC Palliat Care*. 2020;19(1):16.
- [5] Ferrell BR, Twaddle ML, Melnick A, Meier DE. National consensus project clinical practice guidelines for quality palliative care guidelines. *J Palliat Med*. 2018;21(12):1684-89.
- [6] Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Jiang Kwete X, et al. Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage: The Lancet Commission Report. *The Lancet*. 2018;391(10128):1391-54.
- [7] McIlfratrick S, Muldrew DHL, Hasson F, Payne S. Examining palliative and end of life care research in Ireland within a global context: A systematic mapping review of the evidence. *BMC Palliat Care*. 2018;17(1):109.
- [8] Daya A, Sarkar S, Kar S. Estimation of palliative care need in the urban community of Puducherry. *Indian J Palliat Care*. 2017;23(1):81-87.
- [9] Tatum PE, Mills SS. Hospice and palliative care: An overview. *Med Clin North Am*. 2020;104(3):359-73.
- [10] Dumanovsky T, Augustin R, Rogers M, Lettang K, Meier DE, Morrison RS, et al. The growth of palliative care in U.S. Hospitals: A status report. *J Palliat Med*. 2016;19(1):08-15.
- [11] Ntizimira CR, Nkuriyimfura JL, Mukeshimana O, Ngizwenayo S, Mukasahaha D, Clancy C, et al. Palliative care in Africa: A global challenge. *Ecancermedicallscience*. 2014;8:493.
- [12] Cherny NI, Cleary J, Scholten W, Radbruch L, Torode J. The global opioid policy initiative (GOPI) project to evaluate the availability and accessibility of opioids for the management of cancer pain in Africa, Asia, Latin America and the Caribbean, and the middle east: Introduction and methodology. *Annals Oncol*. 2013;24(Supplementary xi):07-13.
- [13] Clark D, Baur N, Clelland D, Garraida E, López-Fidalgo J, Connor S, et al. Mapping levels of palliative care development in 198 countries: The situation in 2017. *J Pain Symptom Manage*. 2020;59(4):794-07.
- [14] May P, Normand C, Cassel JB, Del Fabbro E, Fine RL, Menz R, et al. Economics of palliative care for hospitalized adults with serious illness: A meta-analysis. *JAMA Intern Med*. 2018;178(6):820-29.
- [15] Sullivan DR, Teno JM, Reinke LF. Evolution of palliative care in the department of veterans affairs: Lessons from an Integrated Health Care Model. *J Palliat Med*. 2022;25(1):15-20.
- [16] Palliative care for non-communicable diseases: A global snapshot in 2015: summary of results from the 2015 WHO NCD country capacity survey [Internet]. [cited 2022 Jun 23]. Available from: <https://apps.who.int/iris/handle/10665/206513>.
- [17] Sharkey L, Loring B, Cowan M, Riley L, Krakauer EL. National palliative care capacities around the world: Results from the World Health Organization Noncommunicable Disease Country Capacity Survey. *Palliat Med*. 2018;32(1):106-13.
- [18] May P, Garrido MM, Cassel JB, Kelley AS, Meier DE, Normand C, et al. Prospective cohort study of hospital palliative care teams for inpatients with advanced cancer: Earlier consultation is associated with larger cost-saving effect. *J Clin Oncol*. 2015;33(25):2745-52.
- [19] May P, Garrido MM, Cassel JB, Kelley AS, Meier DE, Normand C, et al. Palliative care teams' cost-saving effect is larger for cancer patients with higher numbers of comorbidities. *Health Aff*. 2016;35(1):44-53.
- [20] Morrison RS, Dietrich J, Ladwig S, Quill T, Sacco J, Tangeman J, et al. The care span: Palliative care consultation teams cut hospital costs for Medicaid beneficiaries. *Health Aff*. 2011;30(3):454-63.
- [21] Penrod JD, Deb P, Luhrs C, Dellenbaugh C, Zhu CW, Hochman T, et al. Cost and utilization outcomes of patients receiving hospital-based palliative care consultation. *J Palliat Med*. 2006;9(4):973-79.
- [22] Reid EA, Kovalerchik O, Jubanyik K, Brown S, Hersey D, Grant L, et al. Is palliative care cost-effective in low-income and middle-income countries? A mixed-methods systematic review. *BMJ Support Palliat Care*. 2019;9(2):120-29.
- [23] Dalal S, Bruera E. End-of-life care matters: Palliative cancer care results in better care and lower costs. *Oncologist*. 2017;22(4):361-68.
- [24] Drummond MF, Sculpher MJ, Torrance GW, O'Brien BJ, Stoddart GL. *Methods for the Economic Evaluation of Health Care Programmes*, 3 ed., Oxford University Press. 2005. [cited 2022 Jun 23]. <https://EconPapers.repec.org/RePEc:exp:obooks:9780198529453>.
- [25] Gilbert JA, Shenoi SV, Moll AP, Friedland GH, Paltiel AD, Galvani AP. Cost-effectiveness of community-based TB/HIV screening and linkage to care in rural South Africa. *PLoS One*. 2016;11(12):e0165614.
- [26] Zimmermann C, Riechelmann R, Krzyzanowska M, Rodin G, Tannock I. Effectiveness of specialized palliative care: A systematic review. *JAMA-J Am Med Assoc*. 2008;299(14):1698-09.
- [27] Reid EA, Gudina EK, Ayers N, Tigineh W, Azmera YM. Caring for life-limiting illness in Ethiopia: A mixed-methods assessment of outpatient palliative care needs. *J Palliat Med*. 2018;21(5):622-30.
- [28] Ghoshal A, Damani A, Salins N, Deodhar J, Muckaden MA. Economics of palliative and end-of-life care in India: A concept paper. *Indian J Palliat Care*. 2017;23(4):456-61.
- [29] Smith S, Brick A, O'Hara S, Normand C. Evidence on the cost and cost-effectiveness of palliative care: A literature review. *Palliat Med*. 2014;28(2):130-50.
- [30] Martin EM, Barkley TW. Improving cultural competence in end-of-life pain management. *Nursing*. 2016;46(1):32-41.
- [31] Hawley P. Barriers to access to palliative care. *Palliat Care*. 2017;10:1178224216688887.
- [32] Lunn JS. Spiritual care in a multi-religious context. *J Pain Palliat Care Pharmacoth*. 2004;17(3-4):153-66.
- [33] Giezendanner S, Jung C, Banderet HR, Otte IC, Gudat H, Haller DM, et al. General practitioners' attitudes towards essential competencies in end-of-life care: A cross-sectional survey. *PLoS One*. 2017;12(2):e0170168.
- [34] Saini S, Bhatnagar S. Cancer pain management in developing countries. *Indian J Palliat Care*. 2016;22(4):372-77.
- [35] Chukwunke FN. Ethics of palliative care in late-stage cancer management and end-of-life issues in a depressed economy. *Nigerian J Clin Pract*. 2015;18(7):15-19.
- [36] Marty CM, Carter BS. Ethics and palliative care in the perinatal world. *Sem Fetal Neonat Med*. 2018;23(1):35-38.
- [37] Grignoli N, Di Bernardo V, Malacrida R. New perspectives on substituted relational autonomy for shared decision-making in critical care. *Crit Care*. 2018;22(1):260.
- [38] Kim M. The Problems and the Improvement Plan of the Hospice/Palliative Care and Dying Patient's Decisions on Life-Sustaining Treatment Act. *Korean J Hosp Palliat Care*. 2018;21(1):01-08.
- [39] Cerminara KL. The law and its interaction with medical ethics in end-of-life decision making. *Chest*. 2011;140(3):775-80.
- [40] Barker P. Ethical dilemmas in palliative care. *InnovAIT Educ Inspir Gen Pract*. 2017;10(8):489-92.
- [41] Novack DH, Plumer R, Smith RL, Morrow GR, Ochitill H, Bennett JM. Changes in physicians' attitudes toward telling the cancer patient. *JAMA J Am Med Assoc*. 1979;241(9):897-900.
- [42] Şen M. Communication with cancer patients. The influence of age, gender, education, and health insurance status. *Ann N Y Acad Sci*. 1997;809:514-24.
- [43] Youn G. Ethical considerations in hospice and palliative care research. *Korean J Hosp Palliat Care*. 2019;22(2):49-66.
- [44] Breslin JM, MacRae SK, Bell J, Singer PA. Top 10 health care ethics challenges facing the public: Views of Toronto bioethicists. *BMC Med Ethics*. 2005;6:E5.
- [45] Gouda A, Al-Jabbary A, Fong L. Compliance with DNR policy in a tertiary care center in Saudi Arabia. *Intensive Care Med*. 2010;36(12):2149-53.
- [46] Phua J, Joynt GM, Nishimura M, Deng Y, Myatra SN, Chan YH, et al. Withholding and withdrawal of life-sustaining treatments in low-middle-income versus high-income Asian countries and regions. *Intensive Care Med*. 2016;42(7):1118-27.
- [47] Hamano J, Morita T, Mori M, Igarashi N, Shima Y, Miyashita M. Prevalence and predictors of conflict in the families of patients with advanced cancer: A nationwide survey of bereaved family members. *Psychooncology*. 2018;27(1):302-08.
- [48] Gjerberg E, Førde R, Pedersen R, Bollig G. Ethical challenges in the provision of end-of-life care in Norwegian nursing homes. *Soc Sci Med*. 2010;71(4):677-84.
- [49] Devik SA, Hellzen O, Enmarker I. Picking up the pieces - Meanings of receiving home nursing care when being old and living with advanced cancer in a rural area. *Int J Qual Stud Health Well-being*. 2015;10:28382. Doi: 10.3402/qhw.v10.28382.
- [50] Douthit N, Kiv S, Dwolatzky T, Biswas S. Exposing some important barriers to health care access in the rural USA. *Public Health*. 2015;129(6):611-20.
- [51] Lockie SJ, Bottorff JL, Robinson CA, Pesut B. Experiences of rural family caregivers who assist with commuting for palliative care. *Can J Nurs Res*. 2010;42(1):74-91.
- [52] Kang JH, Jung CY, Park K-S, Huh JS, Oh SY, Kwon JH. Community care for cancer patients in rural areas: An integrated regional cancer center and public health center partnership model. *Korean J Hosp Palliat Care*. 2021;24(4):226-34.
- [53] Giesbrecht M, Crooks VA, Castleden H, Schuurman N, Skinner M, Williams A. Palliating inside the lines: The effects of borders and boundaries on palliative care in rural Canada. *Soc Sci Med*. 2016;168:273-82.
- [54] Pesut B, Robinson CA, Bottorff JL, Fyles G, Broughton S. On the road again: Patient perspectives on commuting for palliative care. *Palliat Support Care*. 2010;8(2):187-95.
- [55] Schulz R, Beach SR, Czaja SJ, Martire LM, Monin JK. Family caregiving for older adults. *Annual Rev Psychol*. 2020;71:635-59.

- [56] Yosick L, Crook RE, Gatto M, Maxwell TL, Duncan I, Ahmed T, et al. Effects of a population health community-based palliative care program on cost and utilization. *J Palliat Med.* 2019;22(9):1075-81.
- [57] Saban M, Patito H, Zaretsky L, Salama R, Darawsha A. Emergency department mortality: Fair and square. *Am J Emerg Med.* 2019;37(6):1020-24.
- [58] Breault JL. DNR, DNAR, or AND? Is language important? *Ochsner J.* 2011;11(4):304-06.
- [59] Rubenfeld GD. Principles and practice of withdrawing life-sustaining treatments. *Crit Care Clin.* 2004;20(3):435-51.
- [60] Prendergast TJ, Claessens MT, Luce JM. A national survey of end-of-life care for critically ill patients. *Am J Respir Crit Care Med.* 1998;158(4):1163-67.
- [61] Soares M, Terzi RGG, Piva JP. End-of-life care in Brazil. *Intensive Care Med.* 2007;33(6):1014-17.
- [62] Buckley TA, Joynt GM, Tan PYH, Cheng CAY, Yap FHY. Limitation of life support: Frequency and practice in a Hong Kong intensive care unit. *Crit Care Med.* 2004;32(2):415-20.
- [63] Aldawood AS, Alsultan M, Arabi YM, Baharoon SA, Al-Qahtani M, Haddad SH, et al. End-of-life practices in a tertiary intensive care unit in Saudi Arabia. *Anaesth Intensive Care.* 2012;40(1):137-41.
- [64] Yazigi A, Riachi M, Dabbar G. Withholding and withdrawal of life-sustaining treatment in a Lebanese intensive care unit: A prospective observational study. *Intensive Care Med.* 2005;31(4):562-67.
- [65] Kim S, Lim A, Jang H, Jeon M. Life-sustaining treatment decision in palliative care based on electronic health records analysis. *J Clin Nurs.* 2022 Jan 12. doi: 10.1111/jocn.16206. Online ahead of print.
- [66] De Nonneville A, Marin A, Chabal T, Tuzzolino V, Fichaux M, Salas S, et al. End-of-life practices in France under the Claeys-Leonetti law: Report of three cases in the oncology unit. *Case Rep Oncol.* 2016;9(3):650-54.
- [67] Bistre S. New legislation on palliative care and pain in Mexico. *J Pain Palliat Care Pharmacoth.* 2009;23(4):415-25.
- [68] Morrison RS. Models of palliative care delivery in the United States. *Current Opinion Supportive Palliat Care.* 2013;7(2):201-06.
- [69] Rochmawati E, Wiechula R, Cameron K. Current status of palliative care services in Indonesia: A literature review. *International Nursing Review.* 2016;63(2):180-190.
- [70] Tariq SM, Hasan M, Haider SA. Palliative medicine in Pakistan: A developing country's perspective. *Ochsner J.* 2018;18(2):114.
- [71] Onyeka TC. Palliative care in Enugu, Nigeria: Challenges to a new practice. *Indian J Palliat Care.* 2011;17(2):131-136.
- [72] Yin Z, Li J, Ma K, Ning X, Chen H, Fu H, et al. Development of palliative care in China: A tale of three cities. *Oncologist.* 2017;22(11):1362-67.
- [73] Khosla D, Patel FD, Sharma SC. Palliative care in India: Current progress and future needs. *Indian Journal of Palliative Care.* 2012;18(3):149-54.
- [74] Cultural aspects of palliative care-UpToDate [Internet]. [cited 2022 Jun 23]. Available from: <https://www.uptodate.com/contents/cultural-aspects-of-palliative-care>.

PARTICULARS OF CONTRIBUTORS:

1. Associate Professor, Department of Paediatrics, Gandhi Medical College, Bhopal, Madhya Pradesh, India.
2. Neonatologist, Department of Paediatrics, Al Jallia Children's Speciality Hospital, Dubai, United Arab Emirates.
3. Associate Professor, Department of Paediatric Surgery, All India Institute of Medical Sciences, Bhopal, Madhya Pradesh, India.
4. PhD Scholar, Department of Neurosurgery, Rutgers, New Jersey Medical School, New Jersey, USA.

NAME, ADDRESS, E-MAIL ID OF THE CORRESPONDING AUTHOR:

Amit Agrawal,
Gandhi Medical College and Kamla Nehru Hospital,
Bhopal, Madhya Pradesh, India.
E-mail: agrawaldramit@yahoo.co.in

PLAGIARISM CHECKING METHODS: [\[Jain H et al.\]](#)

- Plagiarism X-checker: Jun 01, 2022
- Manual Googling: Jun 29, 2022
- iThenticate Software: Aug 30, 2022 (13%)

ETYMOLOGY: Author Origin**AUTHOR DECLARATION:**

- Financial or Other Competing Interests: None
- Was informed consent obtained from the subjects involved in the study? NA
- For any images presented appropriate consent has been obtained from the subjects. NA

Date of Submission: **May 31, 2022**Date of Peer Review: **Jun 23, 2022**Date of Acceptance: **Jun 29, 2022**Date of Publishing: **Sep 01, 2022**