Barriers to Hospice and Palliative Care in Developing Countries and its Moral Implications

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ABSTRACT

While palliative and hospice care were generally well established in most developed countries, with many centres and professionals providing suitable care and treatments to patients in different situations, this type of treatment to patients in their final period of life is almost non-existing in most developing countries.

There are many barriers that impeded the process of development of the palliative care in developing countries. In this paper we discuss the potential barriers to the implementation of palliative and hospice care in developing countries, including its moral implications.

Here, we analyse key topics related to palliative and hospice care and analyse this special type of treatment through three perspectives: its definition and meaning, its potential barriers in developing countries, and its moral implications.

We discuss the similarities and differences among these three terms: palliative, hospice, and curative care and go on to investigate the potential barriers that pose difficulties for this type of end-of-life care to establish in developing countries, especially China and India. We then go on to investigate the moral issues that involve in the practice of palliative care and discuss the critical concepts morality highlighting the typical moral challenges encountered when administering this type of care.

INTRODUCTION

Hospice and palliative cares represent critical components within the medical field as they provide essential supports to patients during their final periods of life. Developed countries have widely embraced this kind of treatment, with numerous hospitals and centres dedicated to offering comprehensive palliative and hospice care. However, a notable disparity exists in developing countries, where a limited comprehension of hospice and palliative care prevails. Consequently, the provision of such care remains scarce, with only a few available facilities accessible to the general public.

To explore this complex issue, this essay tries to present a comprehensive overview of palliative care, providing a detailed understanding of the current circumstance of end-of-life care. Moreover, the essay will explore the potential barriers that hamper the progress and implementation of this type of care within developing countries. By obtaining these insights into these barriers, we could possibly discover the underlying reasons why the general public lack the awareness of misunderstand the meaning of this end-of-life care. Therefore, we can propose some probable interventions and strategies to enhance the impact of hospice and palliative care, especially in developing countries. In conclusion, this exploration not only identifies and examines the potential obstacles hindering the recognition of hospice and palliative care, but also enables us to analyse the true value of this new form of treatment for patients in their final life period.

Also, while exploring the potential barriers to hospice and palliative care, the essay will also discuss the relevant moral issues that involved while practicing the hospice and palliative care. Many people feel unwilling to accept palliative care due to moral considerations. These apprehensions could be possibly explained by a lack of understanding of the meaning of hospice care, causing unnecessary concerns. Those apprehensions may also arise from the traditions of specific countries or regions, preventing the general public there from adopting this new type of care. In addition, the moral issues pose difficulties for government to support this care, putting the propagation and dissemination of hospice and palliative care in a hard place. As a result, it is important for us to understand the specific moral problems of implementing this medical treatment and the consequences of these issues, which are discussed in this essay.

METHODS

For this study we used a systematic literature search and qualitative thematic analysis to investigate the challenges of hospice and palliative care in developing countries and their relevant moral implications. The methodology aims are to identify, synthesise, and critically analyse a large body of academic literature and authoritative sources for building a holistic understanding of this subject.

Study Type and Objective

This study is in principle a narrative review with systematic elements to give a comprehensive account of the current environment, obstacles, and ethical issues in developing countries with regard to hospice and palliative care. The main objectives were to:

- Define and differentiate among palliative care, hospice care, and curative care in the context of end-of-life treatment.
- Identify and categorize the most critical barriers to developing and adopting hospice and palliative care in developing countries, with special consideration of regions such as China and India.
- Explore and discuss the moral and ethical implications of providing or failing to provide hospice and palliative care in these environments.

Search Strategy and Data Sources

An intensive literature search was carried out in a number of databases and authoritative sites to cast a very broad and relevant net. The major electronic databases used were as follows:

- PubMed (or Medline) especially for literature pertaining to the medical and health sciences.
- Google Scholar especially for a wider interdisciplinary search covering a variety of academic fields.
- Search strategy involved combining all keywords related to core constructs of the review. These keywords, with their variations, were used with Boolean operators (AND, OR) to maximize relevance and coverage. Example search terms included:
  - (""palliative care" OR "hospice care" OR "end-of-life care")
  - AND (developing countries OR low-income countries OR middle-income countries OR global south OR China OR India)
  - AND ("barriers" OR "challenges" OR "obstacles" OR "gaps" OR "impediments")
  - AND ("moral implications" OR "ethics" OR "ethical dilemmas" OR "values")

Date Range and Language: No restrictions were placed on dates; therefore, inclusion applied to both foundational and historical works, but a bias toward more recent sources would be instituted to reflect contemporary issues and challenges. Only works in English would be considered for inclusion.

Access of Other Sources: Further relevant information was sourced from the more authoritative publications such as reports by recognized international organizations (e.g., World Health Organization-WHO, United Nations Population Fund-UNFPA) and relevant books held by academic libraries. These sources rated highly for their contribution of critical contextual data, statistics, and foundational knowledge.

Source Credibility and Selection Criteria

A novel approach was applied in this regard to justifying the reliability and validity of the information presented.

- **Primary Inclusion:** Emphasis was laid on peer-reviewed academic articles published in prominent journals

quite recognized for their accuracy and scientific rigor.
- **Secondary Inclusion:** Reports and guidelines from official international health organizations such as WHO and AAHPM were included on the grounds of their authority regarding factual information.
- **Other Sources:** Relevant chapters in academic books by eminent authors in medicine, ethics, or social sciences were also included.
- **Exclusion:** Non-peer-reviewed articles, opinion pieces without empirical back-up, and articles from unverified websites or organizations were generally excluded, unless offering distinctive and well-substantiated perspectives on the scope.

At screening, titles and abstracts were reviewed for relevance to research questions. The full-text articles and reports were also obtained for critical appraisal concerning methodological quality, credibility, and applicability to the barriers and ethical issues revealed in hospice and palliative care in developing countries.

Data Extraction

Main information extracted systematically from the selected resources should include the following:

- Definitions and conceptual distinctions of palliative, hospice, and curative care.
- Identified barriers to implementation (e.g., economic, cultural, educational, infrastructural, policy-related).
- Specific examples or country-specific case studies from developing countries (especially China and India).
- Moral and ethical dilemmas discussed (e.g., aggressive symptom management, withdrawal of life support, autonomy, beneficence, justice).
- Author's conclusions, recommendations, and proposed interventions.

Data Analysis Approach

The data collected has been subjected to comparative and thematic analysis through this iterative process:

- **Familiarisation:** Reading and rereading selected literatures to deeply understand their content.
- **Coding-red:** detecting items that showed up across different but related sources: Issues or patterns recurring in challenges and moral issues. Systematic coding of data related to definitions, types of barriers, and specific ethical considerations.
- **Categorisation-grouping:** different but similar codes into broader categories. Example, putting together many resource limitations under "economic and infrastructural barriers," while a range of separate ethical considerations formed themes related to "moral implications."
- **Interpretation and Synthesis:** To identify the similarities and divergences between the various findings and perspectives represented in the literature, a comparative analysis was performed. This put different arguments, evidence, and country contexts side by side, in order to lightly trace some of the nuances of the challenges and moral issues.
- **Drawing Conclusions:** The conclusions were well justified starting from synthesized evidence, backed by major data points and largely with quotes from the reviewed literature, with the intent of sustaining the argument throughout the article. The concern of the analysis was not only in describing the issues identified but rather to evaluate them-they are interconnected-and their influence is much wider.

Palliative care and hospice care: what is this special type of end-of-life care and what are the situations of this care in the developing countries.

- What is palliative care?
  There are generally many definitions of palliative care. According to the World Health Organization, the palliative care is a way to enhance the quality of life of patients who faced life-threatening illness (World Health Organization: WHO, 2020). Physically, this care involves providing specific medicine that can serve to relieve the pain that suffered by patients during their final period of life. Mentally, palliative care fosters a supporting environment for the patients to maintain a positive attitude towards life and live actively until death (Roth and Canedo, 2019). According to American Academy of Hospice and Palliative Medicine (AAHPM), the goal of palliative care is to maintain a high quality of life for both of the patients and their families (Hickman, 2023).

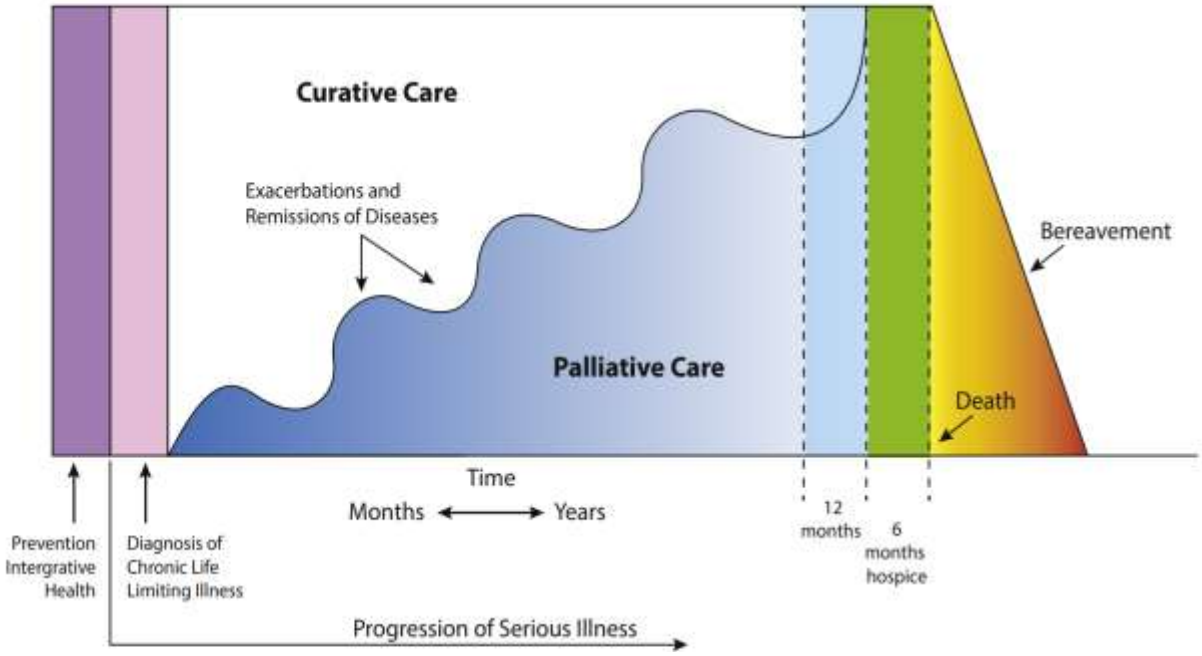
- What are the differences between palliative care and curative care?
  There are significant differences between palliative care and curative care. Curative care focuses on treating a specific type of illnesses, whether obvious or underlying, with the intention of controlling it or curing it (Nikku and Eriksson, 2012). It aims to eliminate the illnesses of the patients completely and restore their health condition (Roth and Canedo, 2019). Some typical examples of curative care are surgery, chemotherapy, radiation therapy, antibiotic treatment, and so on.
  For palliative care, it is a different approach compared to medical care, and has significant distinctions compared with curative care. Instead of aiming to eradicate the illnesses, palliative care is more related to improving the quality of life of the patients. While curative care may cause pain or suffering during the process of treatment, palliative care aims to alleviate those ache to relieve the pressure of the patients. Also, palliative care starts at the time of diagnose and continues throughout the treatment process, which indicates that it generally straddles a longer time period than curative care.
  Nevertheless, it is important to notice that palliative care and curative care are not mutually exclusive. Most of the time, palliative care is applied alongside with curative care, which tries to enhance the general well-beings of the patients as well as fighting with the diseases (Frequently asked questions about palliative care, 2021).
- What is hospice?
  In general, hospice means that patients who have an estimated life-expectancy less than 6 moths give up to continue their curative care (Finestone and Inderwies, 2008). It is a form of compassionate care provided to individuals who are in the advanced stages of a terminal illness. Hospice care aims to provide patients with supports that address both their physical demands and spiritual needs.
  Hospice care is typically provided by nursery centre. It can also occur in the patients' home or some specialized hospice facility depending on the requirements of the patients.
  Hospice also ameliorate the strained emotions of the patients' family. The medical workers will work together with the patients' family to help them maintain a peaceful mental state.
- The relationship between palliative care and hospice.
  Palliative care and hospice are closely related to each other. Both of them focuses on improving the quality of lives of patients. They both aim to enhance the well-beings of the patients through addressing their physical, emotional, psychological, and spiritual problems (Sheikh et al., 2022).
  However, they play distinct roles respectively in providing care for people suffered from severe diseases such as heart failure or cancer. Their differences will be summarized in below:

Firstly, the stage and timing of them are slightly different. Palliative care can be launched at any stage of the illnesses. It can start as soon as the patients' parents or care-takers decide to apply the care regardless of the prognosis or the life expectancy of the patients. Hospice care, on the other hand, is typically provided to the patients when their life expectancy are fewer than six months. Also, hospice care is usually applied to patients at a stage when they give up to pursue curative treatment.

Secondly, the treatment goals are somewhat different for those two types of care. In palliative care, the main goal is to provide comprehensive supports to alleviate the physical and emotional pains suffered by the patients. Usually, curative care was applied along with palliative care in order to seek for the possibilities of recovering. However, for hospice care, the focus of the care shifts to foster a peaceful and dignified environment in patients' end-of-life situations. Curative treatment is no longer pursued alongside with hospice care.

Thirdly, the locations of the two treatment are usually different. Palliative care can be provided in various settings, including but not limiting to hospitals, clinics, and the patient's home. While hospice care is limited in certain places. It is normally delivered in specific hospitals which accept those patients or nursing homes.

Fig. 1. Continuum of care model for patients with serious illness. (Adapted from Lynn J, Adamson DM. Living well at the end of life: adapting health care to serious chronic illness in old age. Santa Monica: RAND; 2003.)



Potential barriers that prevent palliative care and hospice centres from proceeding and processing in developing countries.

China

China is a large country with a population of approximately 1.38billion in 2016 (United Nations Population Fund.: World Population Dashboard, 2017). Moreover, it is also the country that has the third largest areas in the world, which is around 9.6 million km^2 (Hays, 2022). Over the years, the average age of people was rising in China. To this end, more and more people were suffering from severe life-threatening diseases like cancer and heart-failure. These situations elicited the significant increased need for hospice and palliative care service (Lu, Gu and Yu, 2018).

However, for those patients who experienced life-threatening diseases in China, few of them actually received hospice and palliative care. More than 80% of those individuals failed to access any palliative care. Some might even not able to receive oral morphine for pain relief (Knaul et al., 2018). The reason was largely due to their budget limitation. Those individuals lived in low-income and middle-income region, which prevented them to access hospice and palliative care.

The inability of paying for palliative and hospice care was not the only barrier that prevented this type of care to proceed. Actually, there are three main problems in practicing palliative care and hospice. The first one is the limited budget. The second one is that the lack of recognition from society reduces the number of workers in this area. The third problem is the lack of theoretical guidance.

The number of locations which are willing to provide palliative and hospice care is significantly smaller compared to other developed countries like the United States and the United Kingdom. Hospitals in China are struggled to satisfy the need of citizens. Most of the hospitals are usually crowded with mountains of people seeking for doctors. From the survey done by World Population review, the number of intensive care unit (ICU) bed per capital in China is only 3.6, compared to 34.7 for the United States and 29.2 for Germany (ICU beds per capita by country 2023, 2023). Under this background, it is hard for hospitals or centres to allocate resources to support hospice and palliative care, such as providing extra sickbeds or sending nurses. Most of the patients who have an estimated life expectancy less than six months are normally sent to home or transferred to remote centres where no professional doctors or nurses are available to provide palliative or hospice care.

Besides for the lack of medical resources due to limited budget, the cultural belief of Chinese people also place a huge barrier for hospice and palliative care to come into practice. China has a history longer than 5000 years, with feudal dynasties lasted for more than 3000 years. The Republic of China has not been established until year 1912 (History of China | Events, people, dates, flag, map, & facts, 2024). The long period of feudal dynasties results in a profound conservative culture for Chinese people. For this reason, traditional Chinese culture places a great emphasis on pursuing the curative care. People in China usually try to save the lives of the patients at all costs regardless of the recovering possibilities or the thought of patients themselves. Discussion about end-of-life care and health will be considered as a taboo for both patients and doctors. For this reason, the conservative culture influence finally leads to a lack of awareness of seeking palliative and hospice care as a viable options for patients with severe diseases.

The lack of social recognition for hospice and palliative care is also caused by the lack of education. According to The Seventh National Population Census of China, only around 15% of Chinese people obtained an educational attainment junior college and above, which is equivalent to university level (Main data of the Seventh National Population Census, 2021). Due to the limitation of education, many people in China have incomprehensive knowledge about palliative and hospice care. People will also have misconceptions about this type of end-of life care, not fully realizing its benefits and availability. Therefore, Chinese people generally tend to be reluctant in receiving palliative and hospice care.

The last potential barrier is the lack of theoretical guidance. While in developed countries, hospice and palliative care have been practiced for a long time. Medical workers and volunteers have a methodical process of training and providing care. However, in developing country like China where hospice and palliative care have recently been introduced into, the regulation and method of providing palliative care is unclear. Due to a lack of collective guidance provided by government, different organizations or hospitals are not able to unite together. Typically, each organization or centre has its own ways of applying hospice and palliative care. Due to this reason, the quality of those cares may varies from centres to centres. Also, the lack of a collective theoretical guidance will distract the focus of centres which try to provide these end-of-life cares. Every centre needs to put extra efforts in trial implementation and constantly change their own regulations of providing those cares. Therefore, this extra time spent on exploration will prevent them from focusing on improving actual facilities that can provide better care for patients, finally leading to a slow development of palliative and hospice care in China.

India

Palliative care has been firstly introduced to India in the mid-1980s, but the development of this end-of-life care is slow and uneven (McDermott et al., 2008). Also, there is a lot of dearth in the development of palliative care in India. The discussion below will give an overview of India and propose some potential difficulties that pose barriers of developing such care.

India is a country with an estimated population about 1.41 billion in year 2021, approximately one-sixth of the world's population. The population density in India is around 470 people per kilometre square in 2021, which is nearly twice of that in the United Kingdom and more than thirteen times of that in the United States (World Population Prospects 2022, 2022). Such a high number of population and such a high population density lead to a widespread of poverty and low living standard across the citizens in the whole country. In 2000, the World Bank Development report revealed that 89% of the population in India lives on a daily budget less than 2$, and 53% on less than 1$, characterized as "absolute poverty" (McDermott et al., 2008). Although the globalization has impacted positively on Indian economy in recent year, the dense population and a low income level pose a challenging background for palliative and hospice care to develop.

Under this background, there are two major barriers that potentially impede the practice of palliative and hospice care. The first one is the inadequate infrastructure. The second one is the constraints of resources, including limited financial resources and shortages of healthcare professionals.

The inadequate infrastructure in India slows down the development of palliative care. The reasons are obvious. Due to a poor infrastructure, such as a lack of maintenance of highways and roads or insufficient public transportations, people will find themselves struggled to travel into hospitals or care centres when needed. This shortage in infrastructure limited the accessibility of medical services for those people living in remote areas.

For example, people living in rural areas will find themselves particularly troublesome to access proper medical services. Therefore, people tend to delay or even stop short of getting a proper medical approach to their disease, resulting in a low rate of timely and comprehensive care.

Also, a poor infrastructure like inefficient or harmful facilities will have a broader impact on the public health level. People will be influenced unconsciously by the environment they live in, fostering bad habits which pose harm to their health. Therefore, a lack of suitable facilities for people to access in the daily life will increase the rate of getting diseases, which then increase the needs of medical treatment. A high needs of medical treatment will distract the focus on palliative and hospice care. More resources are then allocated to meet the needs of other medical care such as curative care, hampering the development of palliative care.

The shortage of trained personnels and limitation in technology are also potential barriers for the development of palliative and hospice care. Without proper trained staffs like professional nurses or doctors, the quality of palliative care cannot be ensured. Even though patients may overcome the barriers of the accessibility of medical resources, an insufficient number of trained personnels will still place a difficulty that stymie the quality of the care received by patients. Patients may not able to receive the correct or the most suitable palliative care according to their situations. Besides, the limitation in technology will also pose obstacles for patients to receive proper palliative and hospice care. Inadequate technology will prevent patients from receiving the most advanced and up-to-date treatment to their diseases. Therefore, it is a common situation that patients may need to transfer between hospitals or centres where modern technologies are available. During the process of transferring, patients may face the problem of inadequate infrastructure again, involving into a vicious cycles.

Beyond the two major reasons that have been discussed, there are also other reasons such as cultural beliefs and stigma or stringent regulatory policies that pose other challenges for the implementation of palliative and hospice care. In summary, in developing countries like India that have high population and finite resources, the end-of-life cares like palliative and hospice care still have a big space to improve in the future.

Moral issues and problems involved with palliative care and hospice care.

The definition of moral issue:

Moral issue refers to a discussion of moral validation of a certain practice. It usually involves the consideration of right and wrong, fairness and unfairness, and good and evil. People often made their decision taking the consideration of their moral beliefs, traditional values, or ethical principles. Moral issues pertain to lots of different aspects of people, from individuals to organization. Different cultures, religions, and philosophical systems will vary people's recognition on their moral issues, therefore making the discussion of moral issues generally complex and subjective (Reynolds and Miller, 2015).

The similarities between morality and ethics.

Morality and Ethics share a lots of similarities. Their meanings are generally the same. Therefore, the two terms are often used interchangeably in many contexts. Different people and organizations may use these two terms in a slightly different ways, but they usually refer to the same set of objects. Therefore, the boundaries between morality and ethics can be blurred (Gino and Shalvi, 2015).

Firstly, both morality and ethics take the consideration of values and principles. They both revolve around people's fundamental beliefs which guide their behaviours and decision makings.

Secondly, both morality and ethics can be subjective in the extent of discussion. They usually depend on people's cultural norms and society values. Therefore, the consideration of morality and ethics can be varied from individual to individual.

Thirdly, the concept of both morality and ethics is dynamic. They are not static and can evolve over time.

Changes will occur in societal values and cultural values of individuals over the time. This will also lead to a change in their perception of morality and ethics.

The differences between the terms morality and ethics.

While the terms "moral" and "ethical" are often used interchangeably, there are subtle distinctions between them (Grannan, 2023).

Firstly, moral problems are often considered to be more individual and personal. People will decide the right and wrong of a problem based on their viewpoints. By contrast, ethics tend to involve a more systematic overview. Ethics often refers to a set of principles or codes within a people in a certain groups. People in different geological locations may find them having the same way of manners when approaching moral problems.

Secondly, morality is usually more involved with emotions and consciousness. When people approach to moral issues, they generally take into the considerations of their emotions and feelings. Some severe moral problems that will cause strong emotional concerns among people will possibly undermine people's rationalities in making decisions. On the other hand, ethical standards are often established through social agreements or professional codes of conduct. Ethics are more formalized and apply to a broader context. It generally exists beyond individuals' belief, and are shaped by a whole community.

Beneficence and Nonmaleficence.

There are two typical concepts when considering moral issues.

The first principle is Beneficence. It emphasizes that people are obliged to act in a way that maximizes an individual's well-beings. Beneficence points out that people need to prioritize other people's interest and try to achieve the most positive outcomes (Jahn, 2011). In terms of palliative and hospice care, the idea of beneficence states that it is important for people to make the life quality of the patients the top consideration. It is important for medical faculties to prioritize the relief of the pains and sufferings. This can include applying effective pain management, addressing psychological distress, and offering supportive services to improve the overall well-being of patients and their families.

The second principle is Nonmaleficence. It is another concept in morality which states that the focus of the duty should be to avoid causing harm or imposing unnecessary suffering. When this concept comes to palliative and hospice care, it specifically emphasizes the need for medical workers to avoid causing great pain to patients and abusing aggressive medical treatment. Nonmaleficence underscores the importance of ensuring that treatments and interventions align with the patient's goals so that risks can be well assessed and harms do not outweigh benefits.

The first moral issue involving in the practice of palliative and hospice care.

The first moral issue is the ethical dilemma in the use of aggressive symptom management, which may unintentionally hasten the pace of the death of the patients.

This issue involves a balance between the curative medical treatments provided to patients, some of which may be considered to be painful for patients at their end-of-life stage, and the patients' own thoughts and ideas towards the treatment. Medical providers sometimes struggle to choose a suitable treatments for patients for fear of causing further pain to patients as well as unnecessary suffering. The degree to which a symptom management is considered to be aggressive is usually subjective and complex to determine. Therefore, healthcare professionals need to carefully assess whether the treatment will be benefit to the recovery of the patients, or, in opposite, will hasten the rate of death of the patients.

Also, the transparency of the symptom treatment will also greatly involve into the discussion of moral implication. Patients and parents need to be fully aware of their situations from their care-providers. The judgement of whether a management would be considered as aggressive needs to depend on the wishes of patients and their parents. Therefore, open and honest discussions of treatment goals are crucial in tackling the problem of moral dilemma among palliative and hospice care, especially in developing country.

The second moral challenge faced by palliative and hospice care.

Another moral challenge is whether to withhold or withdraw the life-sustaining treatments. This dilemma involves finding a balance between extending life and preserving the patient's dignity and quality of life. Healthcare providers must consider several moral implications when making this decision.

To begin with, the principle of autonomy (Jahn, 2011). of the patients emphasizes that it is important to emphasize patients' right to make their own decisions about what medical care they want to receive. In palliative and hospice care, patients' own choices about whether to continue life-sustaining treatments is crucial.

Secondly, the principles of beneficence and nonmaleficence come into play. Healthcare providers need to assess whether continuing or discontinuing life-sustaining treatments will promote the patients' general well-beings and avoid unnecessary harm. Therefore, medical workers can use methods including but not limiting to prognosis and care goals to achieve comprehensive solution to the moral challenges.

Lastly, the principle of justice is also important, requiring fair distribution of resources and equal access to care. Decisions regarding life-sustaining treatments should be made without bias or unfair considerations, so that it will ensure an equitable allocation of resources for all of the patients in different stages.

After all, it is quite important to note that ethical frameworks and legal guidelines may vary across different countries and regions. Healthcare providers should maintain a global situation when dealing with moral issues in palliative and hospice care, such as consulting applicable laws or asking for institutional policies. Engaging in discussions with morality committees or other organizations can help ensure that decisions regarding the withholding or withdrawal of life-sustaining treatments are made morally justified in each specific context (De Panfilis et al. 2019).

CONCLUSION

While palliative and hospice care were generally well established in most of the developed countries for a long time, with many centres and professionals providing suitable cares and treatments to patients in different situations, this type of treatment to patients in their final period of life was generally unfamiliar to most of the developing countries. There are many barriers that impeded the process of development of the palliative care in developing countries. In the future, whether or not hospice care will thrive in those countries depends on both the government's support of concurring those potential barriers and citizens' recognition of the benefits and drawbacks of palliative and hospice care.

Morality also plays an important part in discussing palliative and hospice care. This end-of-life care included many moral implications that are judged differently by different individuals and organizations. Therefore, medical workers who provide palliative care and patients who receive the treatment need to agree on their moral beliefs and values. Therefore, morality played an important role in the initialization and propagation of palliative and hospice care.

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