World Health Organization (WHO)

Discussing the Access to End of Life Care with Stringent Criteria: Examining Patient Rights in Cases of Unbearable Suffering, Ethical Considerations, and Legal Implications

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I. INTRODUCTION

The world health organization (WHO) was created on April 7th, 1948, and it's headquarters are located in Geneva Switzerland. The World Health Organization's purpose is to promote the importance of health, to monitor global health and to adjust and create responses to health emergencies by working with the 193 countries that make up the UN. It was created because of the necessity of a global health authority that addresses international health issues, they cover everyone's needs from pregnancy care to elderly care. (Britannica, 2021).

In the year 1945 the brazilian and chinese delegations proposed "Health" as a major aim for the UN, then the diplomats started creating a plan for the creation of WHO. In 1946 61 states representatives signed this constitutions and therefore adopted WHO under the article 57 of the UN charter (Gostin, 2023) .The First Health Assembly was established in Geneva on June 24 1948, with majority of the members forming a part in it.(World health organization, 2020)

The World health organization has had different goals and achievements, like the eradication of smallpox, having the leadership in the global polio eradication initiative, the crucial involvement it had in the HIV/AIDS response, and their leading responses in the outbreaks of Ebola.(Gostin, 2023). The way in which WHO achieves these goals is by various methods, for example, they implement guidelines and provide support to member states by using their technical expertise. WHO coordinates international partnerships, changes policies, and promotes health equity by enhancing vaccines and medication, while also facilitating research and development on the emerging health challenges. WHO plays the most important role in giving guidance to involved countries, in order for them to assess the health emergencies in a smart and efficient way. (Beech, 2020)

Modern medical systems and technology have both change the normal path of end of life cycle, and have extended life expectancies . These technologically advanced treatments have the capacity to make someone's life longer, yet they hold no promises for recovery. (Akdeniz, Yardimci, Kavukcu, 2021) This leaves the patient to make the decision of limiting the medical treatments or continue to see if there are better results, however the ethical problems are shown and come into play when said patient has become unable to make

decisions so the family has to make the hard decision of unnaturally prolonging their life, or to let the natural life cycle continue by terminating with the medical procedures or treatments. Therefore, end of life care has faced various ethical dilemmas. (Karnik, Karnekar, 2016).

The main purpose or aim of this conference is to identify and be able to apply new regulations for end of life care so that patients who are going through unbearable suffering or terminal illness. It is essential for the world in general to have rights for the patients in case the patient or their families need to make the hard decision of not continuing with the medical processes. Which is why, taking into consideration the legal implications and the ethical dilemmas there has to be a discussion with the purpose of having a much easier access to end of life care.

II. HISTORY OF THE PROBLEM

It was in the year 2014 when the World Health Organization established, introduced and approved a global resolution on palliative care (World Health Organization, 2020). Palliative care is one of the first treatments the patient has to go through after learning about their terminal illness (NHS, 2023). Before 2014, there had been many major historical events in relation to end-of-life care due to this being a debatable topic on whether it is ethical or not. In the United States, Japan, Africa, Portugal, Belgium, Germany, and Spain, there have been important movements that gained the attention of a lot of organizations including the World Health Organization and the United Nations (Hurst, L. 2022).

British doctor Dame Cicely Sounders founded the Modern Hospice Movement, which then gave life to end-of-life care. (APCA, 2002) In 1967 at Sydenham, she opened St. Christopher Hospice, in which she believed that with the right care, they could have an end of life that was peaceful and with the minimum amount of pain (Richmond, 2005). This hospice became an inspiration for other countries, like in 1979 Zimbabwe's island hospice which was the first hospice service in a developing country (APCA, 2002).

As in many events and important decisions, there are always ethical dilemmas that the public takes a stand on. There have been many cases when the methods and choices are questionable and in some cases even judged, For instance, healthcare providers may face

situations where they must choose between following policies and acting in the best interest of their patients. . Some of those cases include the participation of various countries, like the USA, Italy, and in the United Kingdom.

Cruzan vs. The Missouri Department of Health

In 1983, Nancy Cruzan was in a critical car accident that left her in a constant vegetative state, requiring artificial feeding and hydration to survive. Cruzan's parents wanted to have her feeding tube removed, claiming that Nancy would not want to live in that state, based on the testimony from Nancy's friends implying such a thing, but the staff refused to do it because it would've resulted in Cruzan's death. Additionally, the Missouri law required clear evidence of a patient's wishes for the withdrawal of life-sustaining treatment. The initial trial court authorized the parent's request, stating that Cruzan had a right to refuse medical treatment just based on her friends' claims of her not wanting to live in such a state, but the decision was appealed by the Missouri Supreme Court, causing the decision from the trial's court to be reversed and ruled in favor of the hospital. The case was decided on June 25, 1990, in a 5-4 decision where the US Supreme Court approved the Missouri Supreme Court's decision, which stated that they needed clear evidence that Cruzan would've wanted her life-sustaining treatment to be shut down. This case established that the right to refuse medical treatment cannot be decided by an incompetent individual, and states may need clear evidence of the individual's desire to end life-sustaining treatment before a family member can end life support. The decision, in this case, demonstrates that states that are interested in conserving life may surpass the right to refuse medical treatment, but it is determined that it is up to the states to decide which requirements they will need in order to take such a decision (Cruzan v. Director, Missouri department of health. 2016).

Eluana Englaro

Eluana Englaro fell into a Permanent Vegetative state (PVS) after a car accident in the year 1992, and she remained in this condition for 17 years. For many years Eluana was kept alive through artificial nutrition and hydration, and during all these years her father Beppino Englaro had been looking to get permission to allow her to die since he stated that Eluana had expressed a desire to not be kept alive artificially. His requests were denied by the courts several times; he began legal proceedings in 1999 to have his daughter's feeding tube

removed. After numerous attempts and challenges over almost a decade, a significant decision was made in July 2008, when the Milan Court of Appeal ruled in favor of removing the feeding tube, recognizing that there was clear and convincing evidence that those were Eluana's wishes (Moreschi, 2013). There was strong opposition to this decision from various political groups, like the Italian Prime minister and the Vatican. The government also tried to intervene in this decision by issuing a decree to prevent this withdrawal of life support, but it was too late. In early 2009 Eluana was taken to a private clinic in Udine where preparations were made to stop artificial nutrition and hydration. The case caused significant political confusion, with the government, president, Constitutional Court, and European Court of Human Rights involved (Moratti, 2012).

Diane Pretty

Diane Pretty was a woman who till the year 2002 was unfortunately dealing with a motor neuron disease (MND) (when specialist nerves in the brain and spinal cord, named motor neurons, stop working, therefore making your bones weak and weak with time) (NHS, 2023). This woman firmly believed and thought that as she had the right to life, she had the right to decide the time and manners of her death. She was suffering and along with her husband, both thought that it would be better for her if she ended her life peacefully instead of suffering in the future. When taking her case to court the judge disapproved and disagreed with the decision, saying that not because they had the right to live that included a right to die (CDD, 2022). After the public heard this story they decided that Diane could do what she wanted with her life because in the UK suicide is not a crime, what was a crime was assisted suicide, which made it not possible for Ms. Pretty to have end-of-life at a hospital with medical care, and had to be on materials that probably made her suffer more than she would've in a hospital. This case is debatable to some public because of the wishes of said woman, and some think that the judges made the right decision not letting her have assisted suicide.

In the UK, assisted suicide and Euthanasia are illegal, which made Diane Pretty make an even harder decision regarding her life and health. She knew that she was going to suffer at the end of her life and she was against that idea, that is why she wanted to end her life in a dignified way. The judges not letting her have her life end the way she wanted because, as they said "the right of life did not include a right to die" makes Diane make the hardest

decision of her life, on whether she would end it herself in an unnatural and painful way, or wait until her sickness naturally ends her cycle (Dyer, 2001).

Euthanasia

Ancient Greece and Rome accepted the idea of euthanasia to relieve suffering, with philosophers like Socrates and Plato arguing on ethics. However, with Christianity, euthanasia became seen as morally wrong, with many believing God should have authority.

In the 20th century, attitudes towards euthanasia changed due to advancements in medical technology. The 1970s saw significant movements advocating for euthanasia and assisted suicide. In recent years, countries have legalized euthanasia or assisted dying, reflecting societal beliefs about life, death, and personal autonomy.(Hiatt, A. 2016)

III. CURRENT SITUATION

End-of-life care refers to the belief that each human being has the right to medical assistance for low to extraordinary pain concerns and to have the physical, emotional, and spiritual needs assessed in an expert manner. End-of-life care has had public attention since 1948 and has recently gained more attention and action from organizations at all levels that make end-of-life care more accessible and functional (Paula, 2016). There have been new projects and new ways in which palliative care and end-of-life care have become accessible to a larger number of people (ACCME, 2024). Additionally, they have changed many aspects of the end of life care image to give the message a larger significance, like the new orange symbol that represents palliative care in a more profound way (WA, 2024). End-of-life care has had many innovations that may seem ethical or unethical for the public. Euthanasia, for example, is legal in some countries and illegal in others (US, 2024).

Orange symbol

Interdisciplinary end of life symposium

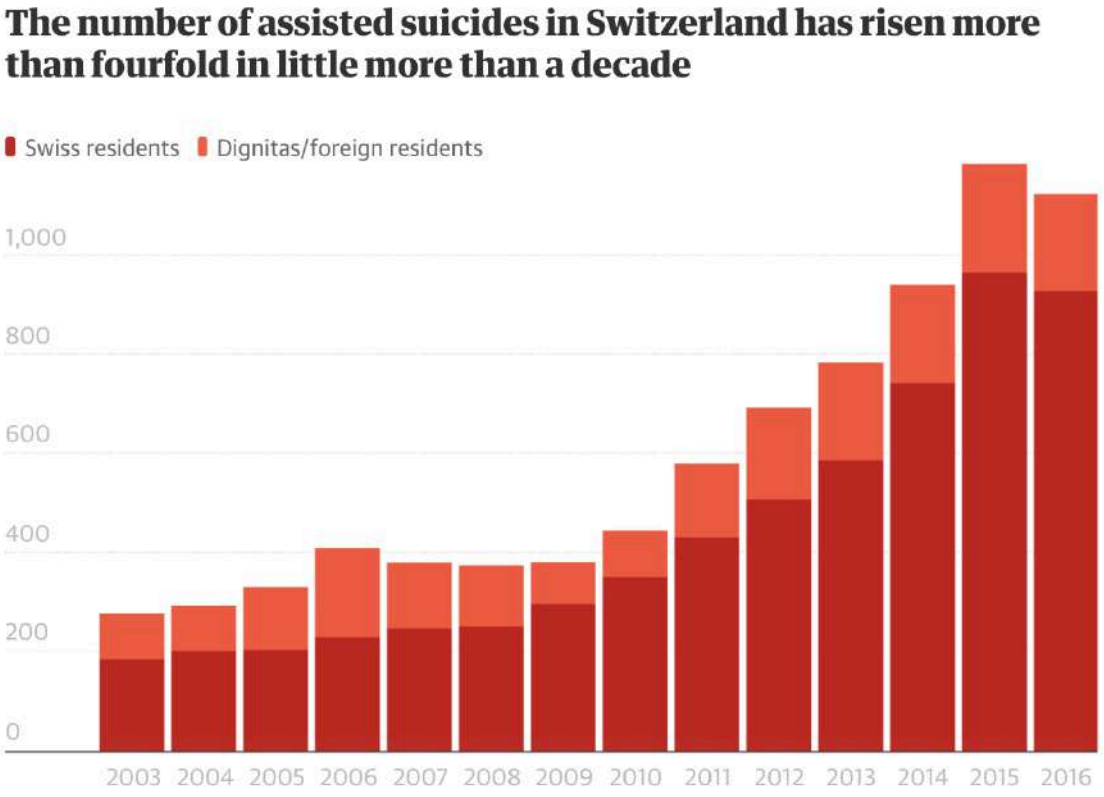
In 2024 new projects were launched that have to do with promoting and implementing a bigger base for end-of-life care. There is a new project in Las Vegas that goes by the name of Interdisciplinary End-Of-Life Symposium, the main focus of this new project is to educate healthcare professionals who will encounter situations of end-of-life care in their career (ACCME, 2024). A symposium is a conference or a meeting regarding one specific topic, and with projects like this one, there will be more awareness and education surrounding the topic (Symposium, 2024). What the End-Of-Life symposium also thinks is that as science and technology advance, the need for more medical treatments and facilities for people in need of end-of-life care must coherently advance as well. Like that symposium, there are conferences all around the world that talk about this subject and the specifics of each country and city's needs. These conferences raise awareness, education, and treatments for the future (Elliot, 2024).

Countries with Legalized and not legalized Assisted Dying or Euthanasia:

The main difference between euthanasia and assisted dying is who carries out the final act. Euthanasia has active steps, that depend on each patient and case, to end someone's life and stop their suffering, while assisted dying is about helping someone take their own life at their request. The Netherlands, Switzerland, and Belgium are considered the most liberal about this topic, and forms of assisted dying or euthanasia are legally permitted (Buchholz, K. 2022). In the Netherlands, both euthanasia and assisted dying are permitted if the patient is experiencing unbearable pain and there is no chance of recovery: requests like this can be made by anybody over the age of 12, but if the patient is under 16 parental consent needs to be given. Euthanasia and Assisted suicide are legal in Belgium, Luxemburg, Canada, and Colombia, however, there are some differences; in Colombia requests for assisted dying can only be made by terminal patients; in Belgium, there are no age restrictions as long as they have a terminal illness. Compared to Euthanasia, assisted dying is more available because of its legality and the simplicity in more places, the self procedure while euthanasia requires a physician, and assisted dying is more ethical at the patient's eye , in Switzerland and many

US states (including California, Colorado, New Jersey, Oregon, Washington, and Vermont), people can choose to end their lives (Davis, N. 2019).

Figures from Switzerland of people who undergo euthanasia or assisted suicide show that the number of those living in the country who underwent assisted death went from 187 in 2003 to 965 in 2015.



(Davis, N. 2019)

On the other hand, in the United Kingdom and in many other countries euthanasia and assisted suicide are illegal. If either of these measures were taken, a murder charge could result in a sentence of up to 14 years in prison (BBC News. 2019). cu. In some countries, it has been legalized while in some others it has huge consequences. Up until 2024, it is still a debatable topic that seems to have no right answer because of how different the public might look at it and its implications.

IV. UN ACTIONS

The UN is an international organization that focuses on and is committed to maintaining international peace and security (Hayes, 2024). The UN has sub-organizations referred to as committees. One of these committees, the World Health Organization (WHO), focuses on finding solutions for health-related issues (CFR, 2022). The UN tries to find solutions and actions that the majority of countries can take in order to resolve different issues. For end-of-life care, the WHO and the UN have taken many actions that highlight the importance of the topic.

1. ***World Health Organization Resolution (2014):***

The UN integrated palliative care into national health systems. Palliative care uses holistic approaches in order to raise the quality of life of patients by preventing suffering through early detection, accurate evaluation of the issue, and treatment of pain, whether physical, psychological, or spiritual. Palliative care is recognized as the human right to health as it treats suffering beyond physical symptoms (United Nations, 2015). Programs for palliative care can assist in addressing the requirements of patients who are very sick as well as their families. Although hospital palliative care programs are widely available, similar treatments outside the hospital are very limited (Palliative Care Action Community, 2014). According to the WHO, each year 56.8 million people require palliative care, however, 14% of them do not receive any of these services at all. To address this issue of the unfulfilled need for palliative care, health professionals must be trained in order to provide universal access to the necessary medications. This integration encouraged member states to develop palliative care policies, which led to an increase in end-of-life care services in several countries (United Nations, 2015).

2. ***Dr. Tedros Adhanom Ghebreyesus :***

An Ethiopian public health official, Dr. Tedros Adhanom Ghebreyesus, who since 2017 has been the director-general of the World Health Organization (World, 2024), made a call in 2021 in order to strengthen palliative care services. After this call was made, in September 2021 states responded stating their support of Dr. Tedros's statement. The member states responded with different actions in order to expand access to those services. Countries like Portugal made laws that included the right to end-of-life care, while some countries created national networks which included palliative care networks, hospice networks, research networks, and

educational networks. Heads of state reported the creation of strategies, actions, and educational programs that were to be developed and implemented in recent years. (WHO, 2022).

3. *Integration:*

The UN, as mentioned, has had many actions taken towards end-of-life care or palliative care, but one that is accessible and can be implemented in many and the majority of countries is to integrate quality improvement methods into the usual practice. This means improving the methods and making it easier for the doctors and nurses to work together and find solutions that help the patient have better end-of-life care. It is a systematic approach that works by improving the quality of the treatment for the patient by designing solutions that involve studying the problem in a deeper way so that as the problem is being identified the solutions are being tried out to see which one works better and faster. It is a method and action that many hospitals and doctors can easily take because of it being research and accessible. It is essential to have a deep understanding of the problem in order to come up with effective solutions (IHS, 2021).

VII. POSSIBLE SOLUTIONS

As end-of-life care encompasses physical, mental, and medical support to ensure patient comfort during those sensitive times, applying and establishing regulations, rules and new ways of helping are now more crucial than ever. The following are solutions and measures that can be taken and implemented worldwide in order to improve end-of-life care:

I. Establishing new end-of-life care guidelines:

A. Placing international guidelines for palliative care such as pain management practices, control of symptoms such as nausea or dyspnea, and psychological support like counseling or spiritual care.
B. Adapting to different cultural contexts by recognizing the existent diversity in beliefs and practices regarding end-of-life care. The new guidelines should be

respectful and should incorporate diverse beliefs while maintaining a high level of end-of-life care (Coolen, 2021).

II. *Promoting educational and training programs for healthcare professionals:*

A. Implementing mandatory training sessions regarding end-of-life care. In these training sessions, effective communication with the patient and their family members and ethical implications regarding each patient case should be covered.
B. Establishing educational sessions in which the professionals can practice communication skills and new techniques and ways to manage end-of-life care situations. This solution will give the healthcare provider a more equipped way of talking with the patient and with the family members of said patient (O'Daniel, 2008).

III. *Assessing end-of-life care into worldwide healthcare services:*

A. Advocating for end-of-life care to be a part of primary healthcare systems worldwide. The integration of end-of-life care ensures that patients who are terminally ill or have chronic illness will have direct and easy access to end-of-life care, and other medical processes that are required (WHO, 2018).
B. Making sure that end-of-life care is accessible in different settings, like in health centers, hospitals, and home care places. Hence, reaching each patient across the different stages of their illness (NIA, 2022).

IV. *Consolidating research and development practices for end-of-life care:*

A. Inciting countries invest in research initiatives that are focused on innovative therapies for patients' pain relief and the management of symptoms in different terminal illnesses. This process should include pharmacological treatments and integrative therapies.
B. Encouraging collaboration between researchers, healthcare professionals, and some pharmaceutical companies to make more efficient the research and development in this area (Nyström, 2018).

V. Ensuring international cooperation:

A. Creating new policies that prioritize the funding of the resources for end-of-life care at both national and international levels. This is crucial for the expansion of end-of-life care methods and resources, and for making sure that all people, regardless of their socioeconomic status, can have access to end-of-life care (Lesparre, 2000).

B. Promoting more accessible and efficient international collaboration between governments, nongovernmental organizations (NGO's), and healthcare organizations, so that they can share resources and best practices to make end-of-life care better worldwide. This solution also promotes a care standard that respects cultural diversity (Rajabi, 2021).

VI. Establishing legal and ethical guidelines regarding Euthanasia :

A. Define a clear criteria for the eligibility of a patient that might require Euthanasia or assisted suicide. This eligibility process includes, terminal illness, consent from said patient, or unbearable suffering. (BBC, 2014)

B. In case the reason for the euthanasia process being in place is constant from the patient, then the consent has to have rigorous verification in order to confirm they really did give their full consent and that it is voluntary (AMSJ, 2012).

VI. COUNTRIES INVOLVED

1. United Kingdom:

The United Kingdom was one of the first countries to be a lot more permissive on end-of-life care, mostly due to the hospice movement that was initiated by Dame Cicely Saunders with the founding of St. Christopher's Hospice in 1967 (What end-of-life care involves. 2022). In England, almost 500,000 individuals pass away annually, one of the main issues is that services aren't consistently integrated, which might lead to a breakdown in communication between agencies and employees (Saunders, 2008). The National Health Service (NHS) is working with the government, partners from the healthcare system, and

community and social enterprise (VCSE) to improve palliative and end-of-life care across the country. These organizations have been taking several actions in order to make end-of-life care more accessible to the population; with national strategies like End of Life Care Strategy which was founded in 2008 where they integrated a larger number of health and social care professionals, patients, carers, and the public in each of the regions (N. H. S, n.d.). Currently, assisted suicide and euthanasia are and will remain illegal under the UK law, but there have been debates and challenges looking to change this law (UK, 2015).

2. *Kingdom of Netherlands:*

In the Netherlands, euthanasia and palliative care are performed; where the physician gives the patient a lethal dose of a suitable medication at their request. Euthanasia and assisted suicide are only legal if the requirements and guidelines established by the Dutch Termination of Life on Request and Assisted Suicide are fully observed. Euthanasia requests are frequently made by patients who are in unbearable pain with no chance of recovery. They must ask "with all of their sincerity and conviction". Patients, however, do not always have the right to euthanasia, and physicians do not always have to carry it out, requests like this can be made by anybody over the age of 12, but if the patient is under 16 parental consent needs to be given (Euthanasia, assisted suicide on request in theNetherlands. 2011).

1. *United States of America:*

The United States of America has a very large number of organizations dedicated to improving palliative care and hospice care. Medicare and Medicaid Services (CMS) is a foundation that was established in 1983, and it has a really important role in controlling and adding hospice care and end-of-life care. It works by providing access to high-quality end-of-life care to patients who are terminally ill (*Medicare Hospice Benefit, 2019)*. There are other organizations like the National Hospice and Palliative Care Organization (NHPCO), which was founded in 1978 and works by giving patients and their family members comfort and peace during end-of-life care and the most vulnerable moments in one's life (NHPCO, 2019). These and many more organizations in the United States find ways to improve policy and expand the research of the end-of-life care area. In the United states of America there are ongoing efforts to integrate end of life care into the country, and they will continue to improve. Although euthanasia is still illegal in the country, physician-assisted suicide is legal in several states, including Oregon and California, but ofcourse under stringent conditions. (Brazier, 2023)

2. ***Germany***:

Germany has established a strong legal framework for palliative care, including the 2007 law requiring the integration of palliative care services in health insurance. With this new law, they allow nationwide specialized outpatient palliative care services, ensuring every patient receives home care. Implementation was expected by 2008, following the creation of corresponding guidelines (Escobar et. al., 2010). Also, the German Association for Palliative Medicine (DGP) plays a crucial role in advancing the field through research, education, and advocacy: it was founded in 1994 and has over 6,000 members from various medical, nursing, and other professional fields that collaborate closely; with 55% being physicians, 30% in care services, and 15% in other fields like psychology, spiritual welfare, social work, and physiotherapy (Dlubis-Mertens, n,d.). Euthanasia is still, also, illegal in Germany, but, once again, physician-assisted suicide was decriminalized by the Federal Constitutional Court in 2020, only if it meets with the legal safeguards (Hänely, 2023).

3. ***Australia:***

The Australian Government implements laws and frameworks in order to ensure that all Australians have access to high-quality palliative care services, regardless of their residence status. Palliative Care Australia (PCA) was an organization founded in 1991 with the goal of advocating for policy changes, research improvements, and promoting education to make end-of-life care services better. This organization works with the consumers, the member organizations, and the palliative care workforce; to improve access and to promote the need for end-of-life care services. PCA supports the health, and the community sector workforce in giving end of life care to people with terminal illnesses. (More, n,d.). Assisted suicide and euthanasia are legal in many states in Australian, like Victoria, Western Australia, and Tasmania, each state has its own regulations and criteria for the practice to be made (ELDAC, 2023).

3. Canadá

4. Japan

5. France
6. South Korea
7. Costa Rica
8. Italy
9. New Zealand
10. Pakistan
11. Switzerland
12. Belgium
13. Colombia
14. South Africa
15. Afghanistan
16. Bangladesh
17. India
18. Finland
19. Sudán
20. Sweden
21. Portugal

22. Cambodia

23. Ireland

24. Denmark

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