Politics of Pain: Investigating the Ethics of Palliative Care as a Global Human Right

Alix Masters

ABSTRACT

Vietnam, a country with a culture strongly imbued with Eastern Buddhist values, has a long history of rejecting palliative care and pain medications in general. Due to this, the World Health Organization' declaration that palliative care is a universal human right could also be understood as a Western organization blatantly ignoring Buddhist cultural traditions. While the declaration of palliative care as a human right is important progress in many ways, it is also important that Western medicine not impose our values globally without consideration for the complex histories and belief systems of diverse cultures.

Keywords: Palliative care, pain management, bioethics, global ethics

INTRODUCTION

Within the last decade, strides have been made in the field of global health policy to extend the reaches of palliative care universally. In 2014, the World Health Organization formally declared palliative care a global human right.[1] This development in global health policy is a positive one when we consider the medical politics of pain relief across racial difference. Both in the United States and abroad, there is a long medical history of discriminatory practices against certain groups of people with regard to pain management—including withholding necessary pain medication altogether. Therefore, in many ways the declaration of palliative care as a human right is a necessary step in ensuring all peoples, regardless of identity, have their pain taken seriously by the medical establishment and have their comfort made a medical priority. When we consider how different cultures negotiate beliefs around death and pain relief, however, the issue of palliative care as a universal human right becomes more complex. For example, countries with strong histories of Buddhist thought and culture have traditionally opposed the ideology of palliative care. [26] In Buddhism, suffering is considered an inextricable part of life and masking this suffering through medical intervention is looked down upon.[2] For example, Vietnam, a country with a culture strongly imbued with Eastern Buddhist values, has a long history of rejecting palliative care and pain medications in general.[26] Due to this, the World Health Organization' declaration that palliative care is a universal human right could also be understood as a Western organization blatantly ignoring Buddhist cultural traditions. While the declaration of palliative care as a human right is important progress in many ways, it is also

© 2017 Alix Masters. This is an open access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction, provided the original author and source are credited.

important that Western medicine not impose our values globally without consideration for the complex histories and belief systems of diverse cultures.

ANALYSIS

Palliative care is defined as specialized medical care aimed at relieving the symptoms and stress of terminal illnesses. It is meant to increase the quality of life for someone suffering from a very serious illness without the prospect of recovery. Palliative care often involves the administration of strong opioid medication to relieve severe pain associated with symptoms of advanced disease, as well as provide overall comfort to the patient. Palliative care differs from hospice care in that palliative care can be provided along with treatment and does not have concrete time limitations. While hospice care is typically provided by a hospice nurse in the patient's home or caretaking facility, usually for a patient very close to death, palliative care is provided by a physician typically in a hospital setting for patient who are not necessarily facing imminent death.

In 1992, the medical law scholar, Margaret Somerville, argued relief from suffering is both the goal of palliative care and human rights, and therefore palliative care should be considered a human right.[3. Since then, many international health institutions have made statements declaring palliative care as a human right.[4] In 2002, the Cape Town Declaration of South Africa declared palliative care, and its associated access to strong opioid pain killers, a universal human right for all its citizens. In 2005, the government of Quebec released the Montreal Statement on the Human Right to Essential Medicines which made explicit arguments for the provision of palliative care as part of the international human right to health.[5] Most notably, in 2006, Pope Benedict XVI made a statement emphasizing the importance of palliative care as "essential to preserving human dignity," and also argued it be formally considered a universal human right.[6] Then, in 2014, the World Health Organization finally made its resolution declaring palliative care as an essential part of healthcare and urging all countries to ensure access to pain medication and palliative care expertise for all citizens.[7]

The declaration of palliative care as a Human Right is groundbreaking considering the history of medical discrimination in the realm of pain-relief. Western medical practices have a long and sordid history of maintaining discriminatory and false beliefs about pain tolerances across different races. It is well documented that during the time of slavery in the United States there was a standard of belief that black patients had a much higher tolerance for pain than white patients.[8] As a result, black patients were often operated on without anesthesia even though anesthesia was commonly used on white patients. The rationale hinged on the fact that "unlike blacks, [whites] were unable to stand the pain involved" with surgery.[8] One particular documented case of patient Anarcha, a black slave woman and a patient of Dr. Marion Sims, states she endured over thirty experimental gynecological surgeries without anesthesia due to her "alleged superhuman threshold for pain." [9] Infamous slave doctor Samuel Cartwright of the University of Louisiana coined the medical term "rascality," which described the alleged phenomenon of black enslaved people seeming "to be insensible to pain when subjected to punishment."[10] Furthermore, white American neurologist Silas Weir Mitchell, referred to foreign indigenous patients as "savages" who do "not feel pain as we do: nor as we examine the descending scale of life do animals seem to have the acuteness of pain-sense at which we have arrived."[11] This logic greatly contributed to the rationale behind the Tuskegee syphilis experiment of 1932-1972 during which black male syphilis patients were left untreated for their disease or their pain.[12] This racist history of the western medical establishment's false ideas about pain difference across races is essential to consider when we discuss contemporary ideas about access to pain relief, and specifically, palliative care.

It is especially important to consider this history as it is clear this scientifically false and racist belief system concerning pain continues even in today's medical practices. Increasing contemporary scientific data suggests that black patients continue to receive less pain treatment than their white counterparts. This can be seen in a study, published in 2007, which found American physicians were more likely to underestimate the pain intensity of black

patients compared to white patients.[13] A recent study out of the University of Virginia surveying medical students and residents found that "58 percent of the study's general groups said they believed that 'blacks' skin is thicker than whites'."[14] Furthermore, the study showed that these same white medical students and residents were unaware of legitimate medical differences between races. For example, "only half of the residents knew that whites are less susceptible to heart disease than blacks."[15] This phenomenon has become known as the "empathy gap"[16] and it is a global issue. For example, at the University of Milano-Bicocca in Italy, it was found that when subjects "saw white people receiving painful stimulus, they responded more dramatically than they did for black people."[17] Due to these false racist beliefs imbedded in our medical history, black people are also less likely to receive prescriptions for pain killers. Furthermore, a 2000 study out of Emory University found that "74 percent of white patients with bone fractures received painkillers compared with 50 percent of black patients."[18] An article published in 2015 found that black children with appendicitis received pain treatment less frequently than their white counterparts.[19] Given these continued problems in medical prejudice, it is essential that palliative care, and relief from pain and suffering due to an illness, be considered a right and not a privilege.

It is also imperative, however, to consider how other cultures view palliative care and pain relief in general and beyond our borders. For example, nations with strong traditions of Buddhist religious practice historically eschew palliative care techniques. This stems from the fact that a fundamental doctrine of Buddhist teaching is that life is suffering and that mindful acceptance of the suffering is imperative.[20] Furthermore, mindfulness at the time of death is also a major tenet of Buddhist belief.[20] Therefore, pain medications are often rejected because they are considered to corrupt the mind and lead to haziness rather than alertness at the time of death. This complicates the idea of palliative care as a necessity for every human being because it ignores strongly held cultural beliefs that view the tenets of palliative care as inherently sacrilegious.

In Buddhism, pain can be lessened through mindful meditation alone, and therefore, pain killers are unnecessary. Meditation is the only way to reach true comfort and make peace with pain. There is also an inextricable connection between the mind and the body and, therefore, to the cure the body, you must first cure the mind. While it is easy for Western medicine to sneer at another culture's belief in mediation in lieu of medical pain treatment as primitive, meditation has been found in many medical journals to ease chronic pain.[21] In fact, if we interrogate our own Western history of the placebo effect, it is arguable we are engaging in hypocritical cultural condescension when we mock the idea of Buddhist meditation as viable medical pain relief. The placebo effect, a well-documented phenomenon within Western medical drug administration has been proven time and time again to show that simply the belief in a treatment can make someone's condition improve, even when there is no active medication being offered. Since this is a known phenomenon, upon which Western scientific research is mostly based, it is hypocritical of Western medical practitioners to mock or overly critique a belief-based approach to pain management in other cultures.

Vietnam is a country deeply influenced by traditional Mahayana Buddhist culture. [27] As such, Vietnam has been one of the countries strongly opposed to palliative care techniques. In addition to Buddhist culture, views on opioids in Vietnam are particularly complex given widespread opiophobia, or fear of opiates. This phenomenon largely stems from the Vietnam war and HIV epidemic, as well as the nation's high rates of illegal heroin abuse. While Vietnam has been an exporter of opium for many centuries, it was not until the Vietnam War that injectable heroin became an epidemic in Vietnam. Since the latter half of the 20th century, Heroin use has grown into a pervasive problem in Vietnam, "with an estimated 20,000 addicts, it has the highest prevalence of injection drug abuse in Southeast Asia." [22] Injectable heroin is also the leading cause of HIV infection in Vietnam with an approximate 60% of HIV cases reportedly due to infected needles." [23] Therefore, in Vietnam, opioids are often closely associated with HIV infection, strengthening notions of widespread opiophobia. All of this coupled with the previously discussed overarching Buddhist culture, this fear of opioids persists even in cases of legitimate medical necessity or pain relief. A study on opioid pain medication availability in Vietnam states "we have found exaggerated fears that morphine and other opioid pain medicines will harm patients by causing respiratory depression or addiction, negative language about opioids in Vietnamese laws and Prime Ministerial decrees, and

highly restrictive opioid prescribing regulations issued by the Ministry of Health."[24] It is no surprise, then, that Vietnam's consumption of medical morphine is miniscule. In fact, according to researchers at the Pain & Policy Studies Group at the University of Wisconsin, Vietnam ranks 122 out of 155 countries studied for their medical morphine use.[25]

Despite the clear schism between palliative care and Buddhist faith, there are important connections between these belief systems that should be culturally explored. For example, both focus on accepting the inevitability of death. Palliative care is considered radical in the medical community because it argues that dying is not a failure of medicine but rather an unavoidable part of life that should be embraced and handled with as much dignity as possible. Similarly, Buddhism also stresses the importance of accepting death, as accepting the inevitability of death of all creatures is what originally inspired the Buddha to renounce the material world and devote himself to mindfulness and meditation. Both palliative care and Buddhism also share the goal of approaching death peacefully. It is simply in the methods that the tenets of palliative care and Buddhist belief differ. While traditional western palliative care advocates for the use of pain relief medication to promote comfort and peace before death, Buddhist teaching advocates for alert mindfulness and meditation and an embracing of pain. It is important to recognize our differences but also our shared values even across difference as a way to find common ground and hopefully promote cross-cultural understanding and respect.

CONCLUSION

Overall, the issue of naming palliative care as a human right has both positive and negative aspects that need to be considered in the field of ethics. On the one hand, taking into account the western medical world's long and continued history of underestimating the pain of, and withholding pain treatment from, patients based on their race, the declaration of palliative care as a human right can be seen as a clear progressive step towards ethical justice. However, the western medical establishment must also take into account differing cultural ideas about death and pain relief before it declares what is best for all people. Due to its Buddhist culture and more recent history of heroin abuse stemming from the Vietnam War, the Vietnamese are logically wary of the methods of palliative care. It is important that this critique of palliative care be understood and respected by the western medical profession and World Health Organization. It is essential we preserve the bodily autonomy of Vietnamese patients to refuse palliative care without judgement or condescension. Rather than focusing on trying to convince cultures of western's medicine's superiority, we should be focusing our efforts in making palliative care economically and socially accessible to all who want it.

- [1] "UN: WHO Boosts Hope on Pain Relief, Palliative Care." *Human Rights Watch*. N.p., 16 Sept. 2015. Web. 06 July 2017.
- [2] Masel, Eva K. et al. "Life is Uncertain. Death is Certain. Buddhism and Palliative Care." Journal of Pain and Symptom Management, Volume 44, Issue 2, 307 312
- [3] Khan, Farzana. "Palliative Care Is a Human Right." Academia.edu Share Research. N.p., n.d. Web. 06 July 2017.
- [4] Khan, Farzana. "Palliative Care Is a Human Right." Academia.edu Share Research. N.p., n.d. Web. 06 July 2017.
- [5] Khan, Farzana. "Palliative Care Is a Human Right." Academia.edu Share Research. N.p., n.d. Web. 06 July 2017.
- [6] Khan, Farzana. "Palliative Care Is a Human Right." Academia.edu Share Research. N.p.,n.d. Web. 06 July 2017.
- [7] "UN: WHO Boosts Hope on Pain Relief, Palliative Care." *Human Rights Watch*. N.p., 16Sept. 2015. Web. 06 July 2017.

- [8] Wall, L. L. "The Medical Ethics of Dr J Marion Sims: A Fresh Look at the Historical Record." *Journal of Medical Ethics*. BMJ Group, June 2006. Web. 06 July 2017
- [9] "Meet the GynePunks Pushing the Boundaries of DIY Gynecology." Motherboard. N.p., n.d. Web. 06 July 2017.
- [10] "Diseases and Peculiarities of the Negro Race." PBS. Public Broadcasting Service, n.d. Web. 06 July 2017.
- [11] Bourke, Joanna. "Pain Sensitivity: An Unnatural History from 1800 to 1965." *The Journal of Medical Humanities*. Springer US, 2014. Web. 06 July 2017.
- [12] Hoffmana1, Kelly M., Sophie Trawaltera, and And Jordan R. Axta. "Kelly M. Hoffman." *Proceedings of the National Academy of Sciences*. National Acad Sciences, n.d. Web. 06 July 2017.
- [13] Staton, L. J., M. Panda, I. Chen, I. Genao, J. Kurz, M. Pasanen, et al. "When Race Matters: Disagreement in Pain Perception between Patients and Their Physicians in Primary Care." *Journal of the National Medical Association*. U.S. National Library of Medicine, May 2007. Web. 06 July 2017.
- [14] Somashekhar, Sandhya. "The Disturbing Reason Some African American Patients May Be Undertreated for Pain." *The Washington Post*.
- [15] Somashekhar, Sandhya. "The Disturbing Reason Some African American Patients May Be Undertreated for Pain." *The Washington Post*. WP Company, 04 Apr. 2016. Web. 06 July 2017.
- [16] Silverstein, Jason. "I Don't Feel Your Pain." Slate.com. N.p., 27 June 2013. Web.
- [17] Silverstein, Jason. "I Don't Feel Your Pain." Slate.com. N.p., 27 June 2013. Web.
- [18] Somashekhar, Sandhya. "The Disturbing Reason Some African American Patients May Be Undertreated for Pain." *The Washington Post*. WP Company, 04 Apr. 2016. Web. 06 July 2017.
- [19] MSCE, Monika K. Goyal MD. "Racial Disparities in Pain Management for Appendicitis." *JAMA Pediatrics*. American Medical Association, 01 Nov. 2015. Web. 06 July 2017.
- [20] "Death and Dying in Tibetan Buddhism." PBS. Public Broadcasting Service, n.d. Web. 06 July 2017.
- [21] Bird, Cindy. "Buddhist Meditations to Ease Chronic Pain." *The Huffington Post*. TheHuffingtonPost.com, 31 Oct. 2012. Web. 06 July 2017.
- [22] Foreman, Judy. *The Global Pain Crisis: What Everyone Needs to Know*. New York, NY: Oxford UP, 2017. Print. /.latest_citation_text
- [23] Foreman, Judy. The Global Pain Crisis: What Everyone Needs to Know. New York, NY: Oxford UP, 2017. Print.
- [24] Krakauer, Eric L. et al. "Toward Safe Accessibility of Opioid Pain Medicines in Vietnam and Other Developing Countries: A Balanced Policy Method." Journal of Pain and Symptom Management, Volume 49, Issue 5, 916 922.
- [25] Foreman, Judy. *The Global Pain Crisis: What Everyone Needs to Know*. New York, NY: Oxford UP, 2017. Print./.latest_citation_text
- [26]"Journal of Social Work in End-of-Life & Palliative Care." *Journal of Social Work in End-Of-Life & Palliative Care*. N.p., n.d. Web. 14 July 2017.
- [27] Hinton, Ladson, Jane NhaUyen Tran, Cindy Tran, and Devon Hinton. "Religious and Spiritual Dimensions of the Vietnamese Dementia Caregiving Experience." *Hallym International Journal of Aging: HIJA*. U.S. National Library of Medicine, 01 Jan. 2008. Web. 14 July 2017. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2949976/>.