Palliative Care in India

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Abstract

This essay addresses the cultural, ethical and political barriers throughout the historical and contemporary context of Palliative Care implementation, prioritization and progress in India. It touches upon the conflicting forces that arise between Western models of Palliative Care and the cultural perspectives on end of life care in India. It poses solutions and methods for navigating these challenges and discusses the communities who are most impacted by the lack of Palliative Care (PC) programs in India.

Palliative Care in India

The term Palliative Care refers to a form of care that is specific to people who are suffering from a life-threatening illness or disease (Ragesh, 2017). The World Health Organization (WHO) describes Palliative Care or PC to be "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (Ragesh, 2017). Palliative Care aims to create a network of support for both the patient and their family. It also supports the family through their bereavement process and grief. Pain management on all spheres, whether physical or psychological, is at the core of Palliative Care. Globally, it is estimated that every year over forty million people need PC (Ragesh, 2017). Seventy eight percent of those people come from a low socioeconomic status and lack the resources to receive proper care (Ragesh, 2017). India is a country that has not prioritized Palliative Care as a healthcare practice or accessible public service. India has deeply struggled to provide policies that support PC, education and drug distribution. As a result, poor rural communities are most impacted. Much like the countless challenges that exist with healthcare services in India, accessible PC is a service that is not widely promoted or practiced in India.

The history of PC in India gives context to the contemporary issues and their origin. The first Palliative Care program started in 1986 and is known today as the Shanti Avedna Sadan (Rajagopal, 2012). Within several years after the Shanti Avedna Sadan had formed, two other branches in Delhi and in Goa were born (Rajagopal, 2012). Unfortunately, patients who were not located near these institutions did not have access to them and this continues to be a serious

issue. The rural and urban disparity is a prominent hindrance in the healthcare of India to this day. In regards to PC, the primary clinics are located in urban settings. Many low-income communities do not have access to services that provide education or medication for pain. The programs that do exist in urban cities were formed primarily by NGO's such as PPCS (Pain and Palliative Care Society) and have been the leading forces in encouraging the government to provide PC support, as well as the ability to access physician-administered drugs like morphine for pain relief. Access to these drugs has been the spearhead of demand for implementing PC services in India. Given the high prevalence of terminal illness in India, drug access and pain management have been leaders in pushing people to campaign for PC support from NGO's.

More than 20 percent of India's population lives with a terminal illness (Rajagopal, 2012). Cancer is one of the leading causes of death in India, with higher numbers of people affected in rural and low-income communities (Rajagopal, 2012). More than one million people each year are diagnosed with cancer in India and often times at a later stage, after the disease has already become terminal. Nearly all of those people experience moderate to severe pain as a result of terminal cancer (Ganga Pram, ND). Given the low numbers of PC facilities in India, countless cancer patients and terminally ill patients are without resources to understand the symptoms of their disease, lack psychological support and are living in painful conditions. "In India, nearly one-half of patients seeking cancer treatment are unaware of their diagnosis or treatment" (Sharma, 2013). A study found that over 52% of people living with a terminal illness were not properly informed or educated about their diagnosis. In all of the cases throughout the study, the relatives of the family member who was dying did not receive accurate information about the disease. Given the lack of education around terminal illnesses in India, it is important that PC services are aimed towards this disparity within education. Awareness and education

regarding a life threatening disease is one of the first steps in PC and has been beneficial in alleviating fears of the unknown and allowing those facing a terminal illness to gain awareness of their disease (Ragesh, 2017).

Lack of education is not the only barrier in the prioritization and implementation of PC in India. A prominent hindrance is the inability to access drugs used to alleviate pain. Opioid availability is strictly governed and difficult to obtain. "Less than 3% of India's cancer patients have access to adequate pain relief" (Rajagopal, 2012). Ironically, India is the world's top distributor of medical opium products though most of the drug is shipped to Western countries (Ragesh, 2017). Compared to many drugs, morphine is not expensive. The cost is not the primary barrier but instead the strict laws that surround Opioid use (Ragesh, 2017). These restrictions have been in place since 1985 and many doctors are unfamiliar with the benefits for pain management. Pain management for terminal illnesses is a focal topic of concern for PC services in India, both in necessity and accessibility. India's long history of government control and culture dictate the use and distribution of opioids. In 1985, India implemented a Narcotic Drugs and Psychotropic Substances Act (Rajagopal, 2012). "In the 13 years which followed the enactment of the NDPS Act, morphine consumption in the country fell by an alarming 92% – from around 600kg to a mere 48kg. In 1997, India's per capita consumption of morphine ranked among the lowest in the world" (Rajagopal, 2012). Strict penalties were enforced for the distribution of morphine. Pharmacies and health centers were instructed to stop providing these substances. Consequently, the effects of this bill are lasting and today people with terminal illness continue to suffer.

Challenges within national healthcare policies and government spending are at the forefront when considering the lack of prioritization of PC, access to pain management and

education services. India relies on a federal system of government to control health and drug

related spending (Rajagopal, 2012). In the context of opioid distribution for PC, each state is

different in their ability to provide services (Rajagopal, 2012). Due to the fact that PC programs

in India are at the beginning stages of development, the obstacles that arise to implement

programs continue to be rampant and are largely attributed to the government's unwillingness to

support such programs.

As stated, India's poor government aid for healthcare services results in the

encompassing factor of low prioritization of PC services. In the larger context of India's

healthcare policies and challenges, PC may not be a top priority when faced with issues such as

infant mortality rates, nutrition and disease prevention. According to the WHO, India is ranked

154th among 195 countries health status (Sharma, 2013). India is the second most populated

country in the world but with only 48 doctors per 100,000 people (Sharma, 2013). The disparities

in India's healthcare creates the argument as to whether or not PC should remain at a lower

priority in comparison to the myriad of healthcare related issues that exist. Population density,

lack of infrastructure, and rural- urban disparity are all factors that contribute to India's current

healthcare status and influence the care that the people of India receive. Though these barriers

exist, NGO groups still take effort to implement PC programs in India and encourage

government forces to recognize the benefits of education and pain management for PC services.

Advocacy for PC programs from international entities has played a significant role in the

growth of end of life care in India. "In 2009, the Human Rights Watch published the results of

their research, named "Unbearable pain: India's obligation to ensure palliative care" (Rajagopal,

2012). This urged government forces to consider the consequences of not providing people with

access to PC, namely drugs to help mitigate pain. Another important aspect that was strongly

promoted by organizations such as PPCS and Human Rights Watch was in educating medical professionals about PC related topics to be incorporated into their practice (Rajagopal, 2012). In 2012, the National Program in Palliative Care was created. Unfortunately, lack of funding and distribution prevents outreach to communities in poor rural areas (Rajagopal, 2012).

When considering further implementation of PC in India, it is integral to take into account the relationship between India's culture and the ways that strategies of western models of PC are being introduced and implemented. The Western medical model is founded on four key values that are based upon their understanding of medical ethics. "(1) Autonomy-patient has the right to choose or refuse the treatment, (2) Beneficence-a doctor should act in the best interest of the patient, (3) Non-maleficence-first, do no harm, (4) Justice- it concerns the distribution of health resources equitably" (Sharma, 2013). These foundations in medicine can at times conflict with cultural, religious and spiritual beliefs in India and thus can result in deterring communities from desiring these systems or utilizing their services (Sharma, 2013). When western models are applied, there can be disharmony between the healthcare provider and the patient in regards to language barriers, communication and culture. Bridging these barriers and creating culturally relevant PC programs is essential in ensuring safe and accessible care. If PC programs are implemented in India by outside forces they must be aware of the differences in models and understand the current climate of healthcare and challenges that India faces. The WHO determined that India would need to become more competent in governmental policy, education and drug availability in order to establish effective PC programs (Rajapogal, 2012).

One push that PPCS has been making is based on creating systems for outpatient support. This entails educating and empowering the families of patients who are dying in their homes, by giving families resources about the illness, their options and bereavement support. Unfortunately

not all families can support their loved ones during their dying process. To emphasize, most of these facilities are only located in larger cities and out of reach for rural communities. As modernization and western culture permeates globally, traditional familial structures in India are transitioning. Historically, multigenerational families would co-inhabit homes together (Opler, 1960). This would ensure a level of care for older generations and people alike. They would often live side by side with their children and grandchildren as well as extended family. With changes in culture through colonization and cross-cultural influence, families are shifting from joint family structure to single family units (Opler, 1960). As a result, more and more people with terminal illness and those in older age brackets are disconnected from a wide network of community support during their dying process. Socioeconomic status is a factor that comes into play when understanding familial structures. "The joint family is more characteristic of upper and landowning castes than of lower and landless castes" (Opler, 1960). Poor and rural communities are more likely to live in singular family units (Opler, 1960). It is these same low-income rural communities that are deprived of accessible PC services due to their geographic location, poverty, caste stigma and a myriad of other factors.

Given that Palliative Care only reaches 1% of the population in India, a lot must be done to ensure that people across all socioeconomic statuses are given the proper resources for understanding their terminal illness. This can be accomplished through accessible education, psychological support and receiving pain management (Ragesh, 2017). Poor rural communities are the most impacted by disease and thus it would be beneficial for PC programs to reach these communities by providing access to education and pain management. Currently standing, the government has not implemented palliative care policies and continues to treat these issues as low priority. Many barriers still exist with funding, support from the government, ethical

dilemmas and legal issues. Although PC is not a high priority in India's healthcare trajectory,

education, drug accessibility, awareness and advocacy should be at the forefront for creating

future programs regarding PC.
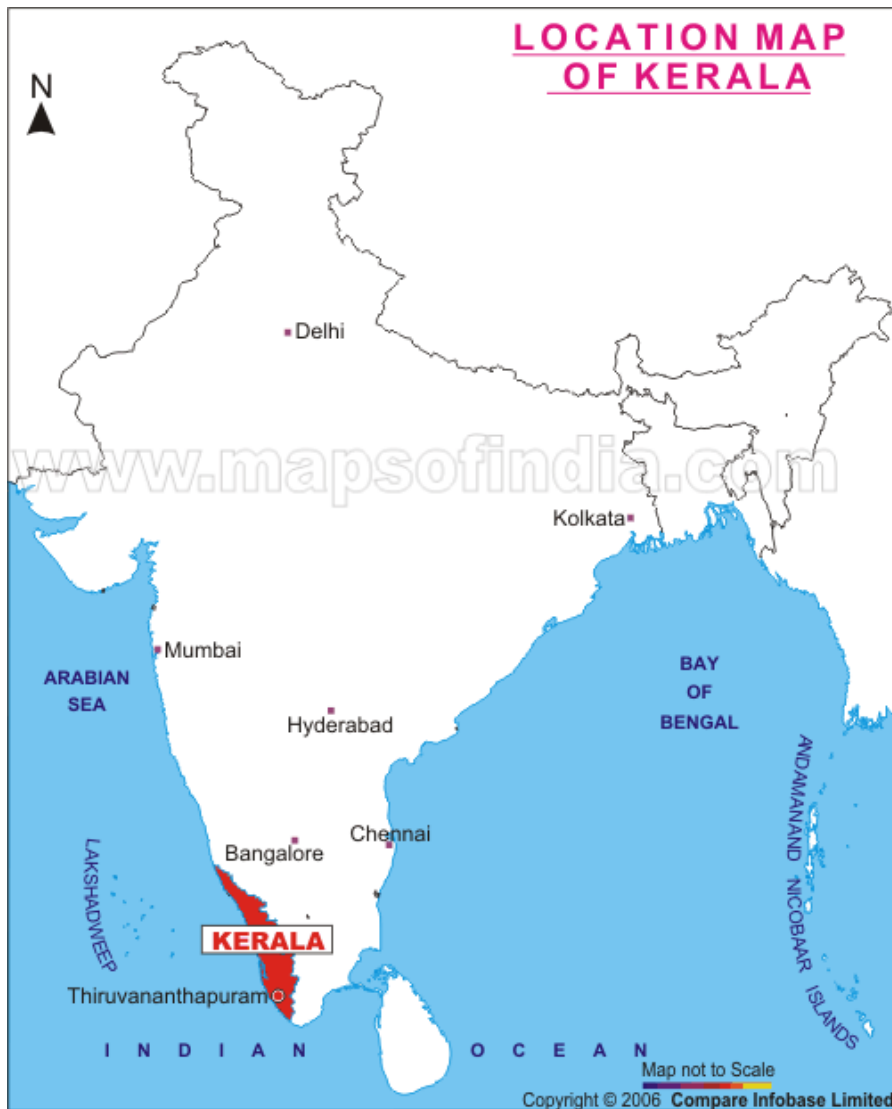
*This is the where PC programs have been most significantly implemented. Kerala has set a standard for other countries in PC models.

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