

# Cultural Construction of Health, Diseases, Illness, and Healing: An Empirical Understanding of “Pain Culture” in India

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**Abstract:** The concept of ‘culture’ could be traced back to Greco-Roman civilization and emerged as scientific product during 18<sup>th</sup> century. The discipline of anthropology identified culture as its subject matter, propounded the concept like ethnocentrism and validated holistic perspective. The human socio-cultural process came to be viewed as an extension of the biological process. Thus, the complex whole definition of culture justifies health as inclusive capabilities acquired by human as a member of a society and progress continued with diversity and change. In the postmodern era, the existing ‘*culture in health care*’ is striving for integration and holism. Health care cultures have simultaneously evolved along with the advancement of human civilizations with an aim of relieving human suffering from diseases and illness. The biomedical establishment and healing evolved as a subculture with cognitive worldview of the patients’ disease that results from scientifically identifiable pathogens. The evolution of cultures from ancient to modern times has necessitated these cultures to face each other due to increasing communication and thus conflict arose between the traditional and modern. The present paper substantiates with empirical case analysis of cancer patients in India, establishing that cultural diversity should be a primary concern for health care professionals caring for patients who suffers with pain as their cognitive perception towards health, illness, disease and wellness are culturally oriented. The paper also explores the concept of ‘Pain Culture’ and justifying that it was not only a physiological response but is also a bio-psychosocial phenomenon which emerges at ‘intersection of body, mind and culture and critically evaluates the relevance of inclusive palliative policy in a pluralistic society and justify cross culturally. The paper suggests that the palliative care necessarily be understood as pain management through medicine.

**Keywords:** Cultural Construction, Holistic Wellness, Pain Culture, Pain Management

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## 1. Introduction

The psychic unity of mankind proved that the curiosity of human about the world view of their interest and trying to predict it, in order to evolve, along the changing world has been an aspect of focus in academia. Social scientist, scientifically formulated grand concepts and theories about all the issues of the world which is socio-economic and political in nature and continuously updating. These concepts and theories are trying to give better understanding about all the issues in the world and equip human to deal with it in better

ways in the growth process. Each discipline chose to develop by identifying the domain subject matter of its own and evolve as a popular subject with critical outlook of these theories and concepts. Anthropology, though a late comer in the roll call of social sciences, established as an interesting subject, choosing ‘culture’ as its core element, conceptualised in theories and substantiated universally. Every discipline felt the relevance of anthropological concepts, approaches, methodologies and given due space in their field and trying to update disciplines. The unique anthropological spectrum ranged from socio-economic, political, technological and including all the development indicators.

Anthropologists have been working among the vulnerable communities and trying to understand everyday life situations. Health indicators of these communities occupy the lowest ranking and are unable to reach the minimum standards due to poor living. The multidisciplinary studies focus hard to integrate the methodological approaches and try to fill the existing gaps of the epidemiological outputs. The purpose of such integrative research looks at the issues from a holistic perspective and relatively brings about changes in the field of medicine. It is pertinent to evolve such models in dealing with the chronic diseases like cancer and tackle the problem using alternative methods. The research postulated a serious question that what could be the process of treatment for the disease which is highly stigmatised in the society. The empirical understanding revealed the reality of the research problem studied.

## 2. Conceptual Construction of “Culture” & Health Care

The concept of ‘culture’ could be traced back to Greco-Roman civilization and emerged as a scientific product during the 18<sup>th</sup> century. The discipline of anthropology identified culture as its subject matter and evolved as a distinct discipline by the 2<sup>nd</sup> half of the 19<sup>th</sup> century. Though the works of Aristotle, Herodotus, Hippocrates, Plato, Polybius, Strabo and Tacitus are very important contributors in the field of politics, social and economy, the grand philosophies resulted out of the ethnographic documents of the communities lived then. The ethnocentric perspective of the antecedent social studies given scope for anthropology to construct the culture concept in a holistic perspective and proved its universalism. Culture contact was the main leap of progress and established cultural pluralism in the world. The humanistic ideal of progressive advancement evolved in the beginning as biological and evidences mounting to produce the idea of species variability and directional changes justified through natural selection. The human socio-cultural process came to be viewed as an extension of the biological process and the variations undermined with the concept of objectivity and subjectivity. But the reality proved that culture determines everyday life and vice versa. Thus, the complex whole definition of culture justifies health as inclusive capabilities acquired by human as a member of a society and wellness progress continued with diversity.

The postulated social theories were basically organismic in nature with stress on structural functional connections through part and a whole concept. The evolution of cultures from ancient to modern times has necessitated variations and thus conflict arose between tradition and modern. In the postmodern era, the existing ‘*culture in health care*’ is striving for integration and holism. Besides the criticism, the concepts like ‘Anthroposopic’ by Rudolf Steiner which is purely based on the cognitive methods, results that humanity with nature was comprehensive of spiritual world and at the same time regards itself to be profoundly scientific. All over

the world as well as in India such curative practices are establishing and justifying its prudential application.

The paper substantiates with empirical case analysis of cancer patients in India, establishing that cultural diversity should be a primary concern for health care professionals caring for patients who suffer with pain as their cognitive perception towards health, illness, disease and wellness are culturally oriented. The present paper explores the concept of ‘Pain Culture’ and justifying that it was not only a physiological response but is also a bio-psychosocial phenomenon which emerges at the ‘intersection of body, mind and culture. Culture can affect a person’s response to pain and pain perception, both in the meaning and expression of pain. Pain may be seen as something positive, that it is a sign, which the body is fighting towards recovery or as a test of one’s faith through suffering or even as a punishment. It is important to remember there are variations among individuals within a cultural group with regard to their perception and expression of pain. It is imperative, to view palliative care and policies related to pain relief in a cross-cultural perspective. Palliative care is considered radical in the medical community because it argues that dying is not a failure of medicine but rather an unavoidable component of life that should be embraced and handled with as much dignity as possible.

## 3. Health Dichotomies and Dynamics of Culture

Social sciences perceive health as a total fitness of an individual which would ensure performance of social roles to optimum efficiency. All societies equip their members through the process of socialization and enculturation to play functional roles commensurate with their statuses. Every society establishes health and wellness dichotomies at every stage of growth and ritualised with life cycle ceremonies. Society also provides institutional mechanism to look after the sick with a view to minimize the period and extent of disability and maximize the quantum of recovery in the shortest possible period.

Health is an aspect of culture, that is, way of life of a group or a community which is as equivalent to economic, political, social, and religious aspects of life. All these aspects are interrelated with the structural and functional parts of the society and surface as an integrated whole. The Millennium Development Goals identified health as an important indicator of development and thriving to achieve holistic health along the cultural illness. Health aspects could be classified into ‘soft core of health’ and ‘hard core of health. The soft core represented by ideas about causation of illness, prevention, and promotion of health which could be in the area of faith and belief. The hard-core of health deals with the visible, material aspects such as treatment with medicine. The complex whole culture includes faith, belief, values, morals, norms and so on. The cause-effect relationship of health and illness reflect within cultural belief

system and demonstrated in everyday life. The hard-core health development depends on material growth and it has to be gone well within the cultural cognition.

Health care cultures have simultaneously evolved along with the advancement of human civilizations with an aim of relieving human suffering from diseases and illness. Every individual culture complex has the medical cultures embedded in them. The evolution of cultures from ancient to modern times has necessitated these cultures to face each other due to increasing communication and thus conflict arose between the traditional and modern. With respect to health cultures over the period of renaissance and growth of positivism some therapies are branded as orthodox and some as unorthodox and complementary or alternative. The transnational agencies have recognized the potential of traditional systems of medicine in view of their accessibility both physically and culturally and have advocated for integration of these health cultures in national health systems more so to address the dearth of health care professionals. Integration and differentiation both play a pivotal role in the dynamics of human life, cultures and evolution of societies. The dialectics of growth of human civilization are fuelled by the conflict between opposites and a step forward by integration of opposites.

Napier, A. D. et al. (2014) published a landmark report entitled "Culture and health". Defining culture as "a set of practices and behaviours defined by customs, habits, language, and geography that groups of individuals share". The authors acknowledged that while much progress in medicine had been made as a result of epidemiological and basic science research, the lack of systematic attention to culture was a significant deficiency. They also made a number of recommendations, including that medicine should accommodate the cultural construction of well-being, that culture should be incorporated in health and health care provision and that agency (i.e., human intention and action) should be better understood with respect to culture. [1]

#### 4. Philosophical Variations of "Disease"

In the process of understanding health as a cultural construction, another most popular concept used is 'disease'. Defining the terms 'health' and 'disease' is a central problem in the philosophy of medicine and also an important issue in bioethics. There are three main philosophical approaches applied defining 'health' and 'disease'. Naturalists' definitions are based on scientific theory which attempts to highlight the biologically natural and perceived normal for humans [2-4]. Normativists' believe that our uses of 'health' and 'disease' reflect value judgments [5-8]. Healthy states are those states we desire, and diseased states are those states we want to avoid. Hybrid theorists define 'health' and 'disease' by combining aspects of naturalism and normativism. Their aim is to provide an account of health and disease that captures the virtues but not the vices of naturalism and normativism [9-11]. As we shall see, all three approaches to defining

'health' and 'disease' are problematic. Naturalism does not satisfy its own desideratum of providing naturalistic definitions of 'health' and 'disease'. Normativism attempts but fails to capture how the terms 'health' and 'disease' are used by lay people and medical practitioners [12]. The hybrid approach, like naturalism, incorrectly assumes that we can give a scientific account of the natural states of organisms. There is also a more systematic problem underlying the debate over defining 'health' and 'disease'. When discussing controversial medical cases, two factors are salient: the physiological or psychological states of patients, and the values we attach to those states. Naturalists focus on physiological and psychological states—whether an organ or system is normal or properly functioning. Normativists focus on whether a psychological or physiological state is valued or disvalued. The debate is regrettably polarized: naturalism and normativism each focus on only one of the two factors that are important when discussing medical cases. Hybrid theorists do consider both components, but they do so in an overly restrictive way. For the hybrid theorist, disease only occurs when a state is both dysfunctional and disvalued. As a result, the hybrid approach to 'health' and 'disease' too quickly shuts down the discussion of controversial cases.

Using this distinction, when striving to understand disease etiology among a given population, public health specialists and human ecologists often use a 'multi-factorial model of disease' [13]. This is a model in which there are a number of distinct factors that are thought to contribute to disease in the population. Culture is one of these factors, alongside many others, including: genetics, environment, and so forth. The factorial model that clinically applied proved the relevance of involving anthropologists on a clinical level and it was also possible to reduce the impact of the culture 'factor' on disease prevalence has been proposed.

#### 5. Illness and Cultural Complementation

Complementarity theory postulates that human social coordination is the product of structured psychological inclinations and allied to cultural patterns. The innate localised experiences determine every activity of the individuals and congruent with cultural paradigms. The socialization process facilitates to learn culture-specific coordination strategies that enable them to interact in locally meaningful ways. The evolved cultural likings are complementary in nature. '*Culture, health and illnesses* highlighted that the concept of 'culture' comprises 'system of shared ideas, system of belief, rules and meanings and should be perceived holistically. It underlies and is expressed in the ways that human beings live [14]. The culture is a set of guidelines (both explicit and implicit) that individuals inherit as members of particular society and transmitting these guidelines to the next generation by the use of symbols, language, art, and ritual.

Thus, cultural background has an important influence on many aspects of people lives, including their beliefs,

behaviour, perception, emotions, language, religion, rituals, family structure, diet, dress, body image, concept of space and of time, and attitudes to illness, disease, sickness, health, pain, and other forms of misfortune; all of which may have important implications for health and healthcare. Moreover its influence on health related beliefs and behaviours such as individual factors (age, gender, size, appearance, personality, intelligence, experience, physical state and emotional state), educational factors (both formal and informal, including education in to a religious, ethnic or professional subculture), socio-economic factors (poverty, social class, economic status, occupation or unemployment, discrimination or racism as well as the networks of social support from other people) and environmental factors (weather, population density, or pollution of the habitat, various types of infrastructure available, such as housing, roads, bridges, public transport and health facilities) are germane.

The health care and illness studies focused on the unequal distribution of access to health care facilities. For example, Black report of UK (1982) showed that health could clearly be correlated with income, and people in the poorer social classes had more illness and a much higher mortality than their fellow citizens in the more affluent classes. Globally, in many Western Societies the variations are particularly evident among ethnic, cultural minority groups, immigrants, and native-born populations. In the USA, several studies indicated that, member of minority groups suffer disproportionately from conditions such as *Cancer*, heart disease, diabetes, asthma and other diseases [15].

Medical anthropology focused on concepts of illness and cultural constructions (or perceptions) of illness, which includes the experience of illness, the conditions and the process of dealing with it. People from different cultures tend to label disease differently, and do not necessarily see diseases from the same perspective as biomedical practitioners do. In order to understand the multiple perspectives involved, the difference between disease and illness is a useful distinction. Helman (1994) describes the biomedical establishment as a healing subculture with cognitive worldview as well as disease that results from scientifically identifiable pathogens.

It is high time that medical anthropologists reintroduce the nascent critical perspective, both historical and cultural, into a field in which theoretical debates remain largely amorphous. The anthropological perspective and methodologies serves as complementary, especially for alternative and integrative medicine while conducting ethnography of an integrative medicine clinic.

## 6. Other Related Concepts

Over the decades, the concept of *cultural competence* has become popular among the health planners and doctors, nurses, especially in North America. This has mainly resulted from the increasing cultural and ethnic diversity of the population, and the need to improve communication with minority and immigrant groups, and improve the quality of

their medical care. In U.S the governments take the responsibility of OMH (Office of Minority Health). The cultural competence has contributed several different dimensions such as improving the sensitivity of health professionals to the cultural beliefs, practices, expectations, and background of the patients and their community, beliefs about the origins of ill-health, the greater role of the family in making health – related decisions or the preference of some female patients to be examined only by the female health professional, improving access to health care by eliminating structural barriers to quality health care for minorities, such as providing interpreter services, hospital diets that accord with religious beliefs, shorter waiting times for appointments and culturally appropriate health education.

While talking about the two modes of unhealth and stakeholders' perception on disease, illness and sickness says; the first mode of unhealth is disease and it is purely pathological process and most often physical. The markers used to identify disease may have deviation from a biological norm. There is objectivity about disease which doctors are able to see, touch, measure, and smell. Diseases are valued as the central facts in the medical view. It is in this sense that the patient has often been described as 'the accident of the disease'. The second mode of unhealth is illness. Illness is a feeling, an experience of unhealth which is entirely personal, interior to the person of the patient. Often it accompanies disease, but the disease may be undeclared. Sometimes illness exists where no disease can be found. Traditional medical education has made the deafening silence of illness in the absence of disease unbearable to the clinician. The patient can offer the doctor nothing to satisfy his senses. He or she can only bring messages of pain to the doctor, from an underworld of experience shut off for ever from the clinical gaze. [16]

Had little to say on the fundamental question, 'Why make people patients?' because he began his work with an acceptance of the fact that people are patients. This view stems from a proposition that ill health is always a form of communication; whatever else it may or may not be. According to him 'every illness is the vehicle for a plea for love and attention. One of the commonest conflicts of human is caused by the discrepancy between need for affection and the amount and quality of the affection which the situation able and willing to grant [17].

In recent decades concepts such as 'cultural competence', 'cultural awareness', 'cultural sensitivity' and various other iterations have gained prominence within the healthcare systems and more effectively managing cultural diversities. These (attempted) paradigm shifts have been productive in many respects to focus on cultural diversity as individualised. The individual patient experiences, preferences or outcomes, were viewed as cultural interaction (a product of relationships) and perceived it as institutionally mediated (the outcome of divergent values between person and service provider) component. The importance of culture factors on many different aspects of international health was officially recognized in 1996 by the WHO and UNESCO, who

declared it as the year of Culture and Health. In their joint declaration, the directors Generals of both organizations proposed further avenues for cooperation so that health and culture can be developed in mutually supportive manner which will benefit all human across the world [18].

## 7. Holistic Wellness & Anthroposopic Model

During the late 20<sup>th</sup> century, Dr. Jane Myers and Dr. Tom Sweeney considered the notions of prevention and well-being as they related to individuals overall total health. Wellness is a modern word with ancient roots. As a modern concept, wellness has gained relevance since 1950s, 1960s and 1970s, when the writings and leadership of an informal network of physicians and thinkers in the United States largely shaped the way, we conceptualize and talk about wellness today. Aspects of wellness concept are firmly rooted in several intellectual, religious, and medical movements in the United States and Europe in the 19th century. The emerging paradigms of health and wellness embrace prevention, early intervention, and alternative interventions, with the growing importance on wellness and holistic healthcare in the 21<sup>st</sup> century, the popularity of complementary and alternative medicine has significantly increased in west. In reality the Indian health care system informally apply the holistic wellness in their everyday practice because of the cultural pluralism, but the system has to be formalised and it requires scientific validation.

Pioneered the concept of Anthroposopic was founded in the early 1920 by Rudolf Steiner. It is established in 80 countries worldwide, most significantly in Central Europe. The entire range of all acute and chronic diseases is being treated; with a focus on mother and child diseases, family medicine and so on. Chronic diseases necessitating long-time complex treatments and patients are highly satisfied with this holistic form of healthcare. Anthroposophical medicine is based on the cognitive methods and cognitive results of anthroposophy. Steiner began developing anthroposophy in 1901. Anthroposophy is a view on humanity and nature that is spiritual and that at the same time regards itself to be profoundly scientific. Steiner considered anthroposophy a consequential evolutionary step in the development of Western thought [19].

India, being a culturally and linguistically diverse country, developed several types of traditional medicines in different regions. The Indian communities categorised as Other Backward Class (OBC), Scheduled Caste (SC) and Scheduled Tribe (ST) communities. These communities have a concept of '*Vaithiyar, Maruthuvachi*' (Traditional Medicinal Practitioners) and so on. The Ayurveda in Kerala, Siddha in Tamil Nadu and other types of Indian medicines stand testimony for the prevalence of diverse medical systems in India. Recently, during the 12th plan period, the Union government implemented a scheme called Ayurveda, Yoga, Naturopathy, Unani, Siddha, Sowa-Rigpa and Homoeopathy (AYUSH) for

encouraging the spread of traditional medical systems in India. India has a separate administration department called 'AYUSH' in the Union government and extended similar administrative divisions in States. During the pandemic, these departments were suggesting many alternative medicines, especially in the field of *Siddha* medicine namely *Kabhasura* and trying to prove its validity.

It is pertinent that the above argument justified the relevance of culture and its reflection on health. In all these reflections the severity of health deterioration can be observed through 'pain' and the present paper substantiate that it is culturally oriented, empirically justified with cancer patients.

## 8. Pain and Pain Perception

Pain is not only a physiologic reaction to tissue injury, but also embraces emotional and behavioural responses based on an individual's previous experiences and acumens of pain. Not every culture corresponds to a set of anticipated behaviours or beliefs, so cultural stereotyping can lead to inappropriate assessment and treatment of pain. Chronic pain has severe physical outcome and psychological strain causing it to influence the progression of disease. WHO notes in its cancer control guidelines, "Pain can kill" [20]. Social consequences of pain can lead to the incapability to work, take care for oneself, children or other family members, contribute in social activities, and find peace at the end of life. It is widely-acknowledged that a person's involvement and association of pain is multi-dimensional in nature, relating to culture, emotion, mind, and body. The understanding of pain is also influenced by social circumstances and cultural framework [21]. Culture addresses human behaviour in a specified state. The meaning and expressions of pain may be influenced by people's cultural background [22]. Pain-coping strategies differ in cultural groups, and this may be as significant as differences in perceptions of pain [23]. Pain perceptions and behaviour are profoundly predisposed by culture and by the socio-cultural context of clients [24].

In the background of pain, the Bio- Cultural pain model recommends that the experience of pain is basically comprehended and controlled by social learning and the social correlation process that shapes the impression of people inside a specific culture [25]. These procedures impact a man's impression of, and reaction to, physical signs and manifestations. In this examination, it is guessed that unique social gatherings will express their pain practices in an unexpected way. As it were, culture impacts how individuals express pain; deal with their pain and experience absence of pain. This will decide the accessibility of palliative care of the cancer patients [26]. The bio-cultural model proposed by Bates appears ideally suited for studying variability in pain perception and response within a cultural context. The model incorporates the Gate Control Theory with fundamental social learning speculations and socio-cultural measurements. People learn suitable conduct and passionate reactions by watching the activities of other

people who are socially like themselves. As the main wellspring of social examination and social taking in, the family can transmit its esteems and mentality to its youngsters [27].

The bio-cultural model hypothesises that social procurement from family and gathering participation can impact mental and physiological procedures which can also influence the acumen and balance of agony and distress. Bates stressed that the bio-cultural model embraces that, all physiologically average people, paying little respect to ethnicity, have profoundly similar neuro-physiological frameworks of agony observation. According to Bio-cultural model culture communicates powerful and varied lessons about pain and that the meaning and sources attributed to pain differ greatly across culture and time [28-22]. According to this model, tolerance for pain varies widely not just among individuals but also among groups. Morris (op.cit) points out those prize-fighters, eskimos, day labourers’ romantic poets have a very different relation to pain than stressed out executives or victims of sexual abuse. The essential importance of culture and meaning of culture is intense in case of chronic pain. Offers a meticulous review of current research, showing how chronic pain sweeps in to the sphere of non- biological traits causing family conflicts, economic stress and even emotional trauma, and that the pain lies at the intersection between Biology and culture [29]. Observes that the roots of chronic pain sometimes extent into a distant past. For example, women suffering from irritable bowel syndrome where an organic cause is not clear proved significantly more likely than women with organic inflammatory bowel disease to report a history of severe life time sexual victimization [30].

One way to see how pain entangles itself with meaning and belief can be found at the history of art. For example, the statue known as the Laocoon group which ranks among the most famous works from the Greco –Roman world shows pain absorbed into the context of tragic suffering where defeat and destruction remains larger than life. Christian art on the other hand, also displays various complex understandings of pain reflected vividly from the lacerated flesh of Matthias Grilnewald’s fifth century Christ to Guido Renis’s 17<sup>th</sup> century placid martyrdom of St. Sebastian whose upraised eyes link pain with the theological state called the beatific vision. These representations are not decorative artefacts but implicit guides to conduct. Thus, according to bio-cultural model the ways in which a culture represents pain has much to do with how people will experience it.

According to international human rights law, countries have to provide pain treatment medications as a part of their core obligations under the right to health; failure to take reasonable steps to ensure that people who suffer from pain have adequate pain treatment may result in the violation of the obligations to protect against cruel, inhuman and degrading treatment. According to the International Narcotics Control Board Report 2014, nearly 75 percent of the world population has either no access or inadequate access to treatment for moderate to severe pain and tens of millions of

people around the world, including around 5.5 million cancer patients and 1 million end-stage HIV/AIDS patients, suffer from moderate to severe pain each year without treatment. The report also stated that chronic pain is a very common symptom in cancer and HIV/AIDS as well as in other terminal stages of illness [31].

According to the World Health Organization report on Guidance for Availability and Accessibility of Controlled Medicines, 2011 “Most, if not all, pain due to cancer *could* be relieved if we implemented existing medical knowledge and treatments” [32]. The World Health Organisation also reports that approximately around 80 percent of both cancer and AIDS patients and 67 percent of patients with both cardiovascular diseases and chronic pulmonary diseases will experience moderate to severe pain at the end of life [33]. A recent global review of pain studies in cancer patients found that 60 to 90 percent of patients with advanced cancer experience modest to severe pain [34]. Cancer is more than a biological disease. Cultural factors are involved at every stage in the journey through cancer, from prevention to palliative care. Reports that most countries do not have palliative care polices, pain policies, assimilated palliative care services or hospices that include palliative care as a human right for the caring of cancer patients [35].

Prediction that worldwide the number of cancer cases will double to 21.4 million by 2030, and nearly two thirds of all diagnoses will occur in low- and middle- income countries and 13.2 million cancer deaths simply due to the growth and aging of the population [36]. Dependable and reliable access to strong opioids, such as morphine, is a prerequisite towards delivering quality and efficient palliative care, which is crucial component of global cancer control [37]. However, despite its designation as, morphine is significantly limited, or drastically absent, in many low- and middle-income countries (LMICs), such as India [38]. According to World Health Organization Essential Medications, this problem is significant, as 60% of the world’s cancer deaths occur in LMICs and 80% of patients in these countries present with late-stage, incurable disease [39]. The conceptual and theoretical understanding recognized the research gap and hence, the present research process at empirical level by following anthropological approaches and methods put forth [40].

## 9. Methodology

The study design used both quantitative and qualitative methods to understand the correlation between health and culture following the dichotomy of disease and illness/wellness. The qualitative techniques like interviews (both structured and semi-structured) with a wide variety of stakeholders, including oncologists, nurses and other medical professionals, hospital administrators, palliative care doctors, NGOs, drug control and health officials, cancer patients, people with a variety of other life-limiting health conditions and their relatives. The study followed transacts walk technique and spent a day with many above stakeholders.

Participate observation, Case study, Focus Group Discussion and Life history methods were handy and fruitful in generating data capturing their cognitive perspectives. The content and narrative analysis besides the socio-economic analysis given an insight to the problem studied. The data was enumerated from ESI Institute of Pain Management, Kolkata, West Bengal Permission, Ruby General Hospital, and Chittaranjan National Cancer Institute (CNCI), Kolkata through ESI Institute of Pain Management, Sri *Aurobindo Seva Kendra* and Institute of HYDT Research & Education in Kolkata.

Cancer is on the rise in India, as 2.5 million people living with cancer in India; around 1.6 million are predicted to be in pain and will be in need of palliative care. Alongside these, one million new patients are diagnosed with cancer every year. It is evaluated that only 0.4% of the Indian populace, experiencing cancer and can get access to opioids [41]. According to the Indian Council of Medical Research (ICMR) population-based cancer registry report, by the year 2012, the prevalence of cancer patients in India above the age of 60 will be more than one million [42]. With recent advances, some of the cancers are now having a chronic course, about 75-80% of these are diagnosed at an advanced stage. Patients with “incurable cancer” may now survive longer with palliative oncology interventions. Thus, palliative care is preferably required to be assimilated into comprehensive cancer care programs in India. Cancer pain sustained by many patients in India can be easily reduced. ‘Morphine’, the main medication for treating severe pain, although is inexpensive in India, easy to administer but is widely inaccessible to people who need it.

The lack of access to palliative care in India condemns thousands of patients with life-limiting illnesses to chronic pain and great suffering. South East Asia Region comprises 22% of world palliative care patients and among the SEAR countries highest needs for palliative care were in India and China [43]. Economic Intelligence Unit of Lien Foundation conducted had conducted a study on the quality of death and end-of life care. According to the report India ranked last among the 40 countries that were studied and that access to end-of-life care, quality of end-of-life care services and basic infrastructure needed for end-of-life care was lacking and is miserable. Awareness among public about end-of-life care was very limited and the cost involved in India for end-of-life care provision was very high and out of reach of common people [44].

The Lancet Commission on Access to Pain and Palliative Care reported that 61 million people around the world have “Serious Health-related Suffering” (SHS) which necessitates palliative care; out of this at least 10 million of them are present in India. Most patients with advanced cancer in India are simply sent back when curative treatment is no longer effective. Deserted by the health care system at the most vulnerable time of their lives, people affected with cancer face extreme depression, pain, fear, and agony without professional support. This is distressing, given that over half of all cancer patients in India are at a late stage of the disease,

when they are diagnosed and when curative treatment is ineffective and palliative care and pain management are the only services that may still benefit them. In recent times, the Government of India has acknowledged the need for palliative care and taken important steps to develop it. However, despite awareness about the need for palliative medicine government authorities in India, both at the central and state level, have done too little to make sure that palliative care and pain management services are available, or to facilitate their provision by the private sector or non-governmental organizations [45].

Restrictive government regulations on accessing strong pain medication, ingrained practices among health care professionals hinder adequate pain relief, beside the lack of training and education of health care professionals on palliative care, and the overall absence of palliative services in India. In fact, many state governments to endorse complex narcotics regulations that actively impede the availability of morphine, despite a key recommendation by the central government to simplify them by amending the ‘Narcotic Drugs and Psychotropic Substances Act’ (NDPS Act, 1985) [46]. The Government of India in 1998 recommended that Indian states should adopt Narcotics Regulations in order to make easy availability of morphine. However, even today two-thirds of India’s states have failed to do so and have maintained outdated regulations for opioid medications that, in the words of India’s own national Department of Revenue, deny “easy availability of morphine to even terminally ill cancer patients” and have caused “undue sufferings and harassment” because they are “often too strict and cumbersome.” Due to these regulations, many hospitals and pharmacies do not want to commit the amount of time it takes to go through the bureaucratic steps required to obtain morphine, and thus simply do not stock it. Others find that the bureaucratic intricacies frequently result in shortages and delays as bottlenecks and red tape interrupt the supply chain.

Under the ‘International Covenant on Economic, Social and Cultural Rights’, the Indian government has an obligation to take steps “to maximise its available resources” to achieve progressively all the rights in that covenant, including the right to health [47]. Therefore, the government should ensure that patients who require palliative care and pain treatment can get access to these health services. In particular, it should formulate a plan for the development and implementation of these services, ensure the availability and accessibility of morphine and other medications that the World Health Organization considers essential, and guarantee that healthcare providers receive training in palliative care [48]. The failure of the Indian government to do so violates the Right to Health. The right to health also requires a rational and equitable distribution of resources for healthcare services, based on the health needs of the population. The Indian government, however, while investing considerable resources into cancer and HIV services, has failed to make effective provision of palliative care, even though the need for such services is extremely high. Under the Prohibition of torture and ill-treatment Convention, the Indian government

has a positive obligation to take measures to protect citizens under its jurisdiction from inhuman or degrading treatment such as unnecessarily suffering from life-threatening pain. As the UN special rapporteur on torture and other cruel, inhuman or degrading treatment or punishment has noted, “failure of governments to take reasonable measures to ensure accessibility of pain treatment raises questions whether they have adequately discharged this obligation” [41]. Government of India designated regional cancer which treats a large number of patients who require palliative care either do not stock morphine or do not offer morphine. At the same time these regional cancer centres do not have any health care workers who have been trained in Palliative care. This situation strongly suggests that the Indian government has not taken any positive measures towards availability of Palliative Care. It may thus be liable under the Prohibition of Torture and Cruel, Inhuman, or Degrading Treatment for the unnecessary suffering of patients with severe pain and other symptoms at such regional cancer.

### 10. Result and Conclusion

In 2018, the total of (81514) people have cancer disease (Figure 1) among them, (8151) patients were going to palliative care. High number of cancer incidence like (3693) was observed in female gender than male’s (3046). Rural area showed high number of (3735) of incident compared with urban (3008) area of West Bengal. Among the different districts of West Bengal, North 24 Parganas showed high number of cancer incidence (10997) followed by Bardwan (7285), Nadia (6742), Hoawra (6429), Murshidabad (5536). AlipurDuar (5497) and Hugli (5157) the rest of the districts showed cancer incidence with range of 1224-4252.

Among the different types of cancer, breast cancer showed highest number of incidence (8289) followed by cervical cancer (6820) and Lung cancer (5899), mouth cancer showed (3786) number of cases in the year. In addition, NHL, Esophagus, liver, Gallbladder cancers have 3416, 2988, 2354, 2285 number of cancer incidence respectively.

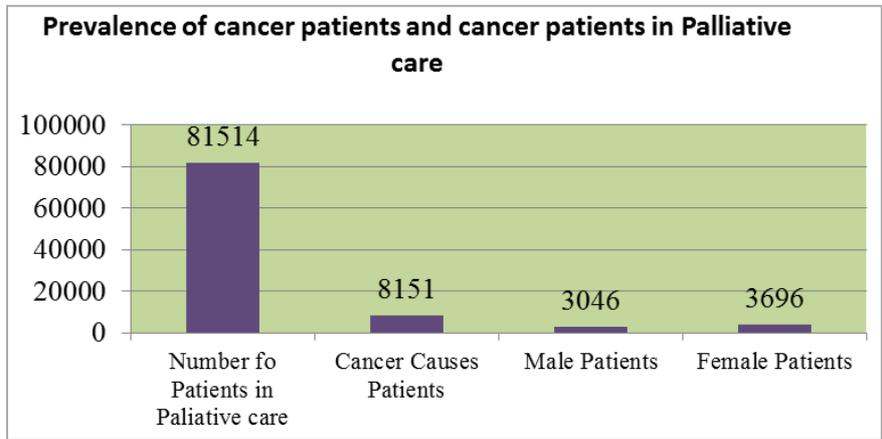


Figure 1. Represents thePrevalence of cancer patients and cancer patients in palliative care.

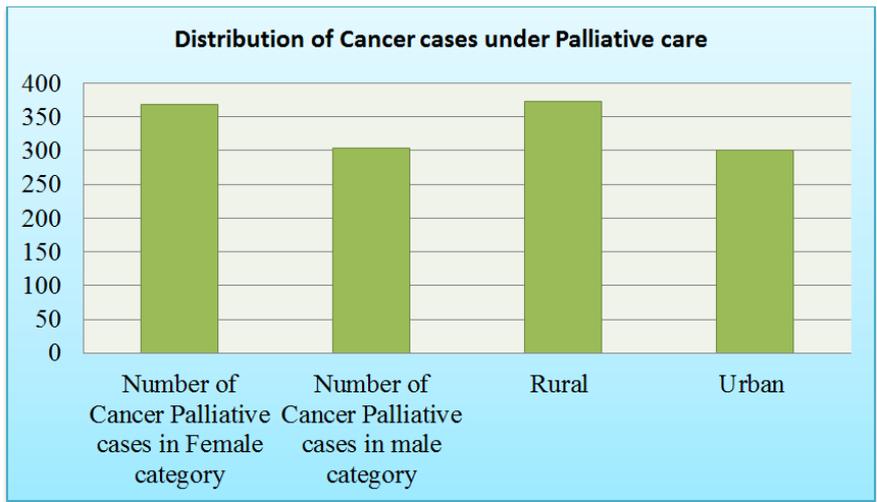


Figure 2. Represents the distribution of cancer cases among the palliative care.

Among the palliative care patients, 369 patients were female and 304 patients were male (Figure 2). High number of rural patients goes to palliative care then urban is about

300 area of West Bengal. Among the different districts of West Bengal, North 24 Parganas showed high number of cancer patients under palliative care (1099) followed by

Bardwan (728), Nadia (674), Hoawra (642), Murshidabadf (553), AlipurDuar (549) and Hugli (515). The rest of districts showed cancer incidence with range of 122-425. Among the different types of cancer, high number breasts and lungs. About 378 number of mouth cancer cases have going to palliative care in the year. In addition, NHL, Esophagus, liver, Gallbladder cancers have 341, 298, 235, 228 number of cancer cares under palliative care respectively.

### 10.1. Conclusion

In India cultural taboos do not allow people to talk openly about some diseases and most particularly cancer. The concept of *Karma* is personified with the patients and mystically relates the issue mostly. Talking or mentioning about breast, cervical or prostate as a body part or affected by the cancer disease, considered as taboo language. Prostate, breast and cervical cancers are highly stigmatized because those 'parts of the body have been associated with sexuality and perceived as a 'most eligible body parts' for marital life. Marriage is an important state of life of an individual and called it as '*gragastha*' and procreation has been perceived as 'completeness'. If an individual could not able to get into the state of life and achieve 'completeness', it is culturally pronounced as worthless. The patients who were affected by these diseases were distained to the society and hardly commiserated. Age, locality, and educational background played a vital factor in treating the patients, as elderly, rural background and illiterates perceived 'low' and have limitation in getting attention. Moreover, these patients come for their treatment when the disease was in an advanced stage. In most cases the patients were reluctance to talk about the symptoms associated with the family members as stigma attached with the disease. Secondly, the person attend to the patient is culturally determined for example wife has to take care when the husband is sick but not vice versa. Similarly, the doctors' gender preference for treating breast and cervical cancer is prevalent.

The palliative patients are willing to talk to 'others' and would like to share their life experiences. The concept of privacy has hardly been maintaining in general and patients also do not make an issue out of it. The pain acts as stressor, due to the advanced malignancy and agitates the security of the framework and influence the personal satisfaction of the client. The indicators of quality life changes for the chronic patients and they perceive 'good health' as the ultimate prosperity and compare with otherworldly physical prosperities, specifically referring gold and housing. The troubling indications like the agony and pain is constantly intervened for the palliative patients and they felt that they had been learning to adjust and change according to the Quality of Life (QoL) sustained for them.

Palliative care patient request for euthanasia as a cry for help demonstrates a sense of hopelessness and highlight the gap in care. The study result indicated that culture has a huge influence on how cancer and cancer palliative care is discussed and managed. It revealed that culture not only affects patients and their family members but it also

influences how families perceive truth about cancer diagnosis, treatment and how they cope with the disease. Sometimes there are conflicting doctor-patient interactions when each is from different ethnic group. Apart from barriers to languages, doctors in the interviews reported that they were not able to address cultural barriers because patients do not volunteer culture-related data as they perceive that they could not understand 'others' practices. The doctors strongly felt lack of awareness about the diseases and patients' right to know about the diseases has never taken seriously in India. The cultural variation especially language, type of food, and belief systems have been taken as a reason for not having transparent communication between the health care professionals and the needy patients. The family institution makes the decision when their member fell sick and receives all the details about the patient. The patient as an individual has very minimal role to play including the treatment process. Cancer is considered a death sentence and therefore frequently referred to in silent tones. This is true for people irrespective of their financial resources. Treatments seem not to offer much optimism, and in many cases, a diagnosis of cancer is kept undisclosed from the patient. Discussions revealed two dissimilar views on disclosure. Those with negative attitudes to a cancer diagnosis believed that fear and worry would kill the patient or make them worse, or that the psychosomatic suffering which results from knowing that one has cancer would decrease the quality of the patient's life. They argued that one should tell the patient that she/he has another disease, while telling the family she/he has cancer and seeking their cooperation in giving the treatment. On the other hand, those having positive outlooks to a cancer diagnosis thought that a patient diagnosed with cancer should be made aware in order to get treatment and to look after oneself. They did not think one can be treated without knowing that she/he had the disease. They noted that treatment was essential and felt that the patient ought to be involved in the process of treatment. The doctors in this study informed that in practice, they do not tell patients they have cancer, but instead they tell a member of the family and that "it depends on the individual patient and the stage of the cancer. They consider that open discussion of serious illness may aggravate depression or anxiety in the patient and may eliminate hope. A patient who is already in pain should not grapple with feelings of depression along with pain. Thus, when the disease knowledge is suppressed, palliative care information is also suppressed from the patients and it is not encouraged as palliative care is often associated with dying. The weight and hair loss was viewed very badly as both the factors were associated with the concept of 'beauty'.

For cancer patients who suffer from chronic pain and often find it difficult to take painkillers orally or through injections, trans-dermal patches can be useful. But these patches are not very popular among the doctors because the usefulness of these patches is not mentioned in the medical curriculum. West Bengal cancer patients face the crisis when it comes to pain management and palliative care. Although hospitals in West Bengal stock morphine to treat cancer pain they only

use it for their own patients, so doctors are forced to prescribe more expensive alternatives such as morphine patches. Unfortunately, this is also out of the reach of cancer patients because in India (and also in West Bengal) Transdermal patches like morphine are also treated as narcotic substances and are subjected to laws like the NPDS Act. As such manufacturers and distributors need licenses from the drug controlling authorities to sell their products. Drug controllers often fail to understand the importance of transdermal patches in offering pain relief. Since 1985 when morphine was branded a schedule H drug, there has been a steady decline in its use and availability.

After a lot of campaigning, morphine has been listed as an essential drug but that has not provided the desired effect as neither the doctors nor the patients give morphine its due importance. Another depressing scene in India, regarding cancer palliative care is the lack of awareness about alternatives and low encouragement to use them. Coupled with scarcity of morphine tablets and transdermal patches patients are also not encouraged for alternative treatments. Another obstacle faced by the patients in using alternative and complementary medicine is that most insurance companies do not cover these alternative therapies. If these services are not covered then alternative medicines such as homoeopathy also becomes less accessible for the patients who are most likely to be impacted by the state’s opioid crisis due to stringent narcotic law.

Identification of the significance of symptom control and other aspects of Palliative Care from diagnosis through the dying process has been growing in India and has reached the national health care agenda through the works of the Health Minister’s Cancer Patient Fund (HMCPF), The National Institute of Cancer Prevention and Research (NICPR), the National Cancer Control Programme. The current inadequacy of palliative care in the state, springs not from the single cause of the sector of society, but from institutional and economic barriers, lack of information and awareness about what can be accomplished, lack of training and education of healthcare professionals, cultural attitudes towards the disease, death and dying, diminutive public-sector investment in research to advance the situation, gender stereotypes, and taboos to mention a few. There is ongoing research to improve this situation but the efforts are not well synchronized and there is a lack of sustained programmes for developing and disseminating palliative treatment. Less than 1% of the budget is spent on any aspect of symptom control, palliative treatment or end-of-life research or training.

The study was commenced as a response to the lack massive need of Palliative Care in the state and that almost 80% of the patients presenting with cancer in West Bengal already have stage four cancers as patients often cannot afford for treatment and seeking alternative treatment. Due to insignificant exposure of general health care in West Bengal, people affected with cancer present late with diseases that may have been treatable in the early stages.

The empirical study has tried to analyse the different institutions comprising the cancer patients,

caregivers/relatives, doctors, nurses, traditional healers dealing with pain perception. The study has also tried to analyse how the pain expression, discriminative words, within the family and the external relatives and the neighbourhood.

1. 50 cancer patients were chosen from the Institute of HYDY Research and Education, Kolkata (Non-Governmental Organization), cancer hospital and pain managements, 90 respondents from the general population comprising common people, care givers, family members, friends and relatives of cancer patients were chosen to understand their perception about cancer, pain and provision of palliative care and how their perception about cancer, cancer pain and provision of palliative care and how their culture influence the same and 100 health care professionals comprising of 50 doctors and 50 nurses were chosen from a governmental pain management institution and a private hospital of Kolkata.
2. Culture related gender role expectations, influenced individual chronic pain experience among cancer were observed to be more sensitive towards their pain compared to male cancer patients in pain. Gender difference in emotions, caused due to cancer patients expressed more emotions and were showed greater signs of fatigue. Pain was also aggravated in female patients when they were unable separate the pain sensation from emotional feeling elucidated by cancer pain and treatment procedures such as chemotherapy.
3. Members of a cultural minority group were also found to receive suboptimal pain management from the health care professionals. The differences in the cultural perception of pain and cancer represented how individuals from different ethnicity theorized cancer pain which is an important subjective element of pain experience. Normalization of cancer adversely affects the health seeking behaviour causing greater pain severity. While belief about cancer pain as enemy may help to develop approaches to encourage patients to seek cancer treatment.
4. Social construction of the disease and pain led to the understanding of the cancer as self-construal comprising. Based on the social construction and cognition of cancer as a disease, cancer patients were found to formulate their own disease perception. Cultural environment was found to have influenced the life-quality of the respondents’ cancer patients and how they perceived and coped with cancer pain and cultural influence on the pain is vast and affects not only perception about pain but influences health, illness, death, cause of the disease and its associated pain, how pain and illness are expressed and experienced, treatment preferences by patients by patients and place of treatment.

## 10.2. Suggestions

The perception about palliative care in India is that it is

confined solely to end-of-life care. Moreover, many oncologists in India consider palliative care as synonymous with palliative medicine. Health care professionals may make an endeavour of not using the term palliative care as a euphemism for dying or death but as a comfort care and symptom management. Palliative care should be thought of as a supplement and complement to medical care right from the early stages of the cancer diagnosis and treatment, adapting itself to the increasing needs of cancer patients and their families if the disease progress into advanced or even the terminal phase. This kind of palliative care should not necessarily be understood solely as pain management though medicine.

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