© 2017. *Social Orbit* ISSN 2395-7719, Vol.3, No.1, pp.53-70.

Embodied Pain and Politics of Palliative Care: A Sociological Study in Calicut District, Kerala

Afeeda K.T
Doctoral Fellow
Delhi School of Economics
Delhi University, Delhi
E-mail: afeedakt@gmail.com

Abstract

Palliative care is a biomedical initiative which offers a holistic approach by adding non-medical aspects of emotion, social, financial and spiritual. It proposes a new model of care against individualistic biomedical care with wider community participation. This study critically looks at the departing juncture of palliative care from biomedicine at both conceptual and practice level. This is a sociological enquiry to see whether Palliative Care is an alternative medical system in dealing with lived experience of pain and conceptualizing the idea of care. Detailed fieldwork is conducted with palliative care clinics in Calicut district, Kerala. It explores the practice of 'holistic care' at three delivery centers of care; clinic, in-patient and home care. Using embodiment as a theoretical framework, the study problematizes the perception and treatment of experience of pain from various networks of palliative care like doctors, nurses and community volunteers. The study finds a gap in the practice of palliative care in understanding the lived experience of pain where factors like language, caste, age, class etc. play crucial role. It also examines how palliative care slips into larger politics of care industry in the medical field.

Keywords: Body, Pain, Palliative Care, Medical Sociology, Embodiment, Illness Narrative, Care Industry, Kerala Health Sector, Institute of Palliative Medicine.

Introduction

We have learned, especially as men, to identify with our minds and segregate and disdain our bodily experiences. We have learned to value reason in a way that has estranged us from our emotional and spiritual lives. We have learned to identify progress with the domination of nature that we can no longer feel at home in. As we no longer feel home in our bodies, we can no longer feel at home with our natural selves (Siedler 1994:84)

Generally, pain is understood as the absence of pleasure. The meaning one connotes to the word pain in daily conversation is different for different people depending on the situation, ranging from physical pain, an expression of mental disturbances or a bad experience or as punishment. Along with differences in the cultural expressions signified by the word ‘pain’, one could also observe similarities in the usage. These generalized understandings of pain are produced discursively at various levels; mainly by the medical practice, religious disciplines and legal definitions.

Biomedical understanding of pain and body is based on Cartesian dualism where physical body is the focus of analysis. How does a patient express his/her physical pain to a doctor? What is the language used for that? How can an outsider who cannot feel the pain of the other person understand it? How this absence of the present pain is understood in a culture? Is physical pain only a feature of the body? These are some of the relevant questions that come to mind when we analyze the setting of a modern clinic where a doctor diagnoses the pain and suffering of a patient.

Studies in medical sociology have criticized the dominant biomedical characterization of pain in our society. Theorists like Foucault (1973) analyzed the historic development of biomedicine and shows with great precision the contingencies of the discipline and the institutional settings in which such knowledge is produced. Studies in medical Anthropology have addressed the lived experience of body and pain. Distinction between illness, disease and sickness (Klienman, 1988), presence of individual, social and body politics (Schepher and Huges, 1987), narrative representation of illness (Good, 1994) etc., are some of the important themes around which subjective experience of patients is theorized. In the discipline of Sociology, influenced by different traditions of post modernism, feminism, phenomenology, post structuralism etc., experiential level of body has risen to prominence in the recent decades. “Embodiment” as a conceptual tool is pivotal in sociological literature to understand the lived experience of pain.

Pain and Palliative care is a biomedical initiative which claims to offer a holistic understanding of patient’s situation, and offers medical aid that is sensitive to the suffering of the body- seen in a larger social, economic, cultural and spiritual context. This trend in biomedicine apart from its socio-political background, informs some interesting questions that form the subject of this paper. The study asks if it is possible in a biomedical field to accommodate non-medical dimensions like social, financial, spiritual and emotional concerns of the patient. If so, what are the forms and practices it adopts? The study examines whether Pain and Palliative care works as an alternative medical system within the medical field, and if so in what specific way. The study is located in Kerala where Palliative care medicine is popular along with other medical systems.

Conceptualization of care in a Palliative medicine is an important focus of this study. In biomedical field, with the profession of nursing, care as a concept is institutionalized, as a transfer of care from the private household to public hospitals. Palliative Care reverses this movement, where care as a concept returns to the sphere of community and home. Individualized approach of biomedicine is then incorporated with a communitarian approach in Palliative Care. This complex and interesting social process is explored in this study.

Understanding body

Modernity and its knowledge system was based on Cartesian dualism which is an indication of its emphasis on science and rationality over non-rational elements like emotions, religion, body etc. This represents an epistemic logic which subsequently came to be reflected in the entire domain of the social, cultural and political reasoning. It informed other sets of dualism like nature/culture, private/public, mind/reason, mind/body etc. It assumes a notion of an atomic individual capable of independent and objective reasoning. Within such framework, body is seen as a physical entity which is to be controlled, developed and put to productive use by the rational mind. Body as an analytical tool is recent in social science discipline. Sociology as a discipline from its classical period itself has avoided body as a focus of study instead dealt with rational man and his/her relationship with society. But later, body became the topic of discussion due to larger interventions in Anthropology, feminism, post modernism etc.

Largely, we can divide these studies into social constructionist and anti-constructionist theories. Social constructionist theories understood body as a product of society. These theories ranges from radical positions which claim that there is no body beyond the social discourse to the positions which discuss social categories which influence body but not necessarily dominate it. These theories tend to agree that body is significantly shaped and produced by society. The work of Foucault (1973) represents an important contribution to the social constructionist understanding of the body. According to him, the body is totally contributed by discourse and subsequently a concrete site for the operation of knowledge/power in modern societies. Interactionist approach of Goffman (1969) explains how society shapes, classifies, influences and controls body. Feminism and post modernism also engage with how existing power discourse constructs gender bodies and critically deals with various modes of its operations. On the other hand, anti-constructionist theoriesunderstand body as independent of any forms of discourse. One category is biomedical perception of body as exclusively physical entity and another is phenomenological approach which addresses faces of embodiment like language, consciousness, emotions etc. which influence actions and process of interactions of social structures and institutions through the body. Merleau-Ponty (1962) uses the concept body-subject to explain how body is produced by society and at the same time society is created and modified by body.In these theories, body is understood either as a product of society or as a subject standing on its own detached from other social institutions and phenomenon.

Embodiment as a theoretical framework

Social constructionist theories outlined above failed to provide an account of the role of human embodiment and autonomy of the lived body. Social constructionist theories miss the complexities of embodiment in relation to the lived experience of the subject and wider cultural and social structures. In line with scholars emphasizing the autonomy of the body and its lived reality, I take the view that rather than looking at body through society/structure/discourse, body should be explored in itself as a sociological unit. In other words, if body is understood as having its own lived, affective, sensuous and tactile ontology that cannot be sufficiently explained within the logic of its social constitution, what kind of social terrain does it open up for investigation?

The body is a corporeal phenomenon which not only is affected by the social systems, but forms a basis for and shapes social relations (Shilling, 2003). Existing narratives on body like foundationalism, anti-foundationalism, phenomenology, social constructionism etc., have not fundamentally challenged the Cartesian legacy which distorts the understanding of reality. An interaction between these positions is required for the construction of sociology of embodiment which demands the recognition of phenomenological basis of a socially constructed body. It is only through the concept of embodiment that we can escape from Cartesian dualism. It is only through this idea that the body can be understood in terms of its corporality, its sensibility and its objectivity (Turner, 1996). Focus on lived experience of body is not a denial of the role of power of social discourses on body but it gives wider ideas on life and body itself. Integration of mind and body is the starting point of such a theory of embodiment (Shillong, 2003; Turner, 1996). Csordas (1990) has clearly emphasized the scope of embodiment as a methodology which address body not as a subject or object but emphasizing its 'bodily-in-the-being'.

Like body, pain is also understood under the same framework; either as a social construct or as a subjective reality. In the former, the autonomy of the body is rejected and the latter does not deal with the physical explanations of pain. The dominant understanding of pain is influenced by biomedical definitions. The International Association for the Study of Pain (IASP)[1] provides a widely used definition of pain as "unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage (1979:250).This biomedical definition of pain makes a clear distinction between physical pain and emotional pain. Bio-cultural model of pain, Morris (1998) tells us that pain is always biological and always cultural. Understanding of pain as a lived experience denies exclusive objectification of pain in body and subjectification of pain with self. Expression of pain and language used also needs attention. Painful body lives in a different world. Language is not always disembodied and exclusive of mind. At the same time, medical language is not the only mode of expression of pain. Multiple realities of a chronic pain are thus expressed in multiple ways.

Pain and Palliative Care

World Health Organisation (WHO) defines palliative care (as an approach)[2]:

> …that improves the quality of life of patients and their families facing the problems 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, psycho social and spiritual.

Palliative Care claims a deviation from institutionalized bio-medical health care and emphasises the concept of 'total care'. The term 'palliative' comes from the Latin word "*pallium*" meaning 'to cloak'. Symptoms are cloaked in palliative care treatment with the primary aim of providing comfort to the patients. Palliative care is part of the health care sector with a multi-disciplinary approach to patients with chronic disease, incurable disease, old age health problems, mental disorders and patients at the end stage of life. The aim of palliative care is to help patients relieve themselves from pain, symptoms and sufferings, to ensure quality of life in the face of intolerable chronic ailments. It provides 'total care' to patients by addressing their physical, psychological, financial, spiritual and social aspects. This holistic care is delivered by both medical and non-medical personnel – doctors, nurses, volunteers and family members.

History of Palliative Care

Palliative Care began as a part of the Hospice movement. Hospice is a place for travelers to rest in the modern inn. This form of Hospice was initiated by Dame Cicely Saunders in 1948, in the United Kingdom[3]. In 1980, the first Palliative care clinics were established in United States in institutions like Cleveland clinic and Medical college of Wisconsin. The basic difference between Hospice care and Palliative care is that the former serves patients at the terminal stage, while Palliative care is provided to patients at all stages of the disease. However, this distinction is vague in practice in many countries.

The concept of Palliative care reached in India in the mi1980s. In India, Palliative care initiatives first began in cancer treatment, primarily based on in-patient medical service. The first Palliative centers were instituted in cancer centers in Ahmadabad, Trivandrum, Mumbai, Bangalore and Delhi. In the second phase, government medical services at various levels initiated palliative medicine. An out-patient clinic was opened in Regional cancer center in Trivandrum and later, with the incorporation of volunteers,the Institute of Palliative Medicine in Calicut enlarged the scope of the practice. Kidwai institute of Oncology in Bangalore is another early institution for Palliative Care. Community participation with medical professionals marked the third stage of Palliative medicine, which included home visits, significantly enlarging the outreach of this practice.

Palliative Care in Kerala

In India, national coverage of Palliative Care is only about 2% while Kerala stands as one of the highest contributors with two-thirds of the total Palliative Care. Palliative Care developed in Kerala with the formation of Pain and Palliative Care Society in Calicut district in 1993. Currently Kerala has more than 200 Palliative Clinics (Institute of Palliative Medicine, registerbook). Kerala is the only state where pain and Palliative Care functions in collaboration with National

Rural Health Mission (NRHM). *Arogyakeralam* Palliative care project in Kerala was initiated in 2008, and is the main implementing arm of the state government's 'Pain and Palliative Care policy'. Institute of Palliative Medicine (IPM) is the nodal agency for implementing this state level project. State policy of Palliative Care which brings together health services, local self-government institutions, Social Welfare Department and Community Based Organizations is implemented at three levels. At the basic level, *Panchayat* Palliative home care is provided by a trained nurse with the participation of health workers, volunteers and elected representatives. At the secondary level, specialist Palliative Care services are made available to a cluster of primary units. Tertiary level Palliative Care services focuses on consolidating activities of the secondary care units by providing training to improve the quality of the Palliative Care services.

Pain and Palliative Care is developed as community based care service in Kerala. The formation of Neighborhood Network in Palliative Care (NNPC) is a turning point in the growth of community based Palliative Care. NNPC is a program that attempts to develop a sustainable community led service capable of offering comprehensive long term care and Palliative Care to the needy in the developing world. It is based on the principle that it is the duty of the healthy in a community to provide care to the unhealthy, and fund raising is carried by the community itself. It aims at empowering local communities to look after the chronically ill and dying patients in that community. Community owned Palliative Care services working all over the state are known as NNPC. Within a decade, the NNPC initiatives have achieved an estimated coverage of 70 per cent in Palliative and long-term care in Kerala. More than 200 individual centers are active within this network. Resources for running these services are raised by the local community. Health care is provided by community volunteers and health professionals. There are of two types of community volunteers: trained volunteers who undergo intensive training to equip themselves to provide emotional support and basic nursing care for the patients; while untrained volunteers are a sensitized group who contribute to the social support system for an active and efficient functioning of Palliative Care. They are involved in fund raising, administrative work, conducting programs to increase the awareness on Palliative Care etc.

Calicut is a district of northern Kerala comprising of 75 Panchayats and one municipal corporation. There are 51 Palliative Clinics in this district.[4] This is larger in number compared to other districts of

Kerala. This trend is a result of an effective strategy and network used for the practice of Palliative Care. In 1993, Pain and Palliative Care Society (PPCS) was established and an outpatient clinic was opened in Calicut Medical College.In the initial stage it was clinic–based, and later expanded its functioning to forge links with various other Palliative initiatives in the surrounding region. Neighbourhood Network in Palliative Care (NNPC) was formed in 1996 in Malapuram district which covers local clinics. Institute of Palliative Medicine (IPM) is an autonomous institution instituted in 2003 with an objective to promote community participation in Palliative care and long term care. It is the nodal agency for Government of India's National Rural Health Mission to implement Palliative care programs in Kerala. The institute is supported by Department of Health and Family Welfare, and Department of Social Welfare of Government of Kerala. IPM is also the policy, research and training arm of the World Health Organization Demonstration Project in Palliative Care. IPM is the only Palliative institution which provides in-patient service.[5]

Study Universe

Out of 51 Palliative clinics in Calicut, 10 clinics have been chosen for this study. All the clinics are either Non-Government Organization (NGO) or Community Based Organization (CBO). The selection of clinics is based on the convenience of access to the clinics. They are Institute of Palliative Medicine, Pain and Palliative Care Society, Government Medical College Unit, Calicut City Pain and Palliative Clinic, Farook Palliative Clinic, Narikkuni Palliative Care Unit, Tanal Pain and Palliative Clinic, Abaya Pain and Palliative Care Society, Daya Pain and Palliative Care Clinic, Santhwanam Pain and Palliative Care Clinic and Nadapuram Pain and Palliative Clinic. Institute of Palliative Medicine is the only institution where in-patient care is provided. It accommodates 32 patients at a time. Patients with chronic or incurable disease get admitted for symptom relief, respite care or for terminal care. Patients who are refereed by health care professionals or community volunteers through community network are usually admitted. City Pain and Palliative Care clinics provide home care service for patients who need regular care at home. All other clinics provide both home care and out-patient service.

Features of Palliative Care

- Accepting death:

Acceptance of the inevitability of death is an important conceptual category in Palliative Care process. Palliative Care is not to hasten or shorten death, but to provide quality of life to people in the final stage of their life. The focus hence is to affect an attitude change towards death. The attempt here is to transform medicalised death into a more natural and less painful process of death. Thus, the primary duty of Palliative Care is to alleviate suffering and to develop different ways to deliver care to the patients and his or her family to reduce the suffering. As a public health strategy, the aim of Palliative Care is to provide maximum care to the majority of the population in a society. It brings into question the general sympathetic or neglectful attitude of society towards patients. Confusion and anxiety are redressed in this mode of providing care by slowly attuning the patient to the reality of impending death. Over-institutionalisation in private medical sectors which alienate patient from his/her world is avoided in Palliative Care.

➢ Total Care:

The holistic approach of Pain and Palliative Care ensures total care for patients with uncured diseases, and in need of physical care to control symptoms of pain and to maintain a minimum quality of life during the ailment. It includes:

a) Physical care: Bio medical interventions predominates Palliative Care to address the physical problems of the patients. It provides minimum medical treatment to ensure a quality of life. Physical care is not to cure the disease but to reduce the pain and suffering. Physical care is provided by doctors and nurses trained in modern medicine. Palliative medicine stresses on the care and basic medical treatment with a personal and social approach. Alternative medicines are usually not encouraged at this stage.

b) Financial care: Patients reach palliative clinics at a stage where all the other treatments have failed, pushing them in to considerable financial crisis. As a respite in such circumstances, Palliative clinics provide treatment and medicine free of cost. Volunteers and nurses visit patients who have registered with palliative clinics and decide on whether the family is eligible for financial support. A decision is arrived at in the weekly meeting of the Palliative care unit. The registration form at the palliative care unit has a column for financial status in which the patients or relatives are required to mention their financial status. It is written as Above Poverty Level, Below Poverty Level and Middle Class, Upper Class or Lower class. The register of the inpatients shows that majority come from lower class.

Home visit also showed the same. Out patients who come for regular checkup express free medical service as a major factor for their choice of palliative Care. The patients from well of families mostly choose Palliative care because of the personal care provided by these clinics, which in their opinion is significantly absent in private or multi-specialty hospitals.

c) Spiritual care: In the beginning of the Hospice movement, spirituality is understood as different from religion. During the final stage of life, questions about the meaning of life, why they were inflicted by the disease and life after death become important existential questions for many patients. Hence addressing them is crucial for alleviating pain in chronically ill patient. The question of spirituality is addressed by developing awareness about patient's state of mind and his/her philosophical confusions about life. An open space for patients to express their mind is provided as a means to engage spiritual and philosophical dilemmas related to death.

d) Emotional care: The approach of Palliative care is based on developing a new, informed and emphatic relationship between the patient, his or her family, their communities and the wider society. Patients with chronic pain who are bedridden for several years suffer from emotional problems of varied nature and intensity. Financial burden of family, sever physical pain, reducing role in social life, fear of death etc produces emotional stress in the patients. Personal approach in Palliative care gives patients a space to talk freely with doctors, nurses and volunteers. Frequent home visits and training the family in basic techniques of redressing emotional trauma are an integral part of Palliative care. Community participation during home visit gives a space to patients for social interaction. In some clinics, psychologists assist patients to deal with their emotional problems. Family and community participation in which doctors or trained volunteers from IPM disseminate information and build awareness about issues related to emotional trauma.

- Palliative Care Network:

It is provided by a network of doctors, nurses and volunteers trained in Palliative medicine. Doctors with MBBS degree are required to obtain a Basic Certificate course in Palliative medicine (BCCPM). Basic Certificate Course in Auxiliary Nursing (BCCPAN) is a similar certification for nurses. Awareness and basic training programme are provided to the volunteers. Palliative courses, along with biomedical aspects, stresses on non-medical dimensions. It emphasizes on communication skill as an important skill for providing total care.

a) Doctors: We find very less number of doctors in Palliative setting. Low payment scale compared to private sector is the major reason-behind this. Apart from government doctors comes under NRHM programme, where palliative service is compulsory, the rest of them consider this as a charity or social service. We can trace this trend to the history of missionary initiatives on social issues. The area of work for these doctors is to provide physical care and rest is compartmentalized as emotional and social pain which is to be dealt by psychiatric department and non-experts like family and community. Medical related decision making comes completely under these doctors.

b) Para medical staff: Minimum qualification required for this post is matriculation. This opens up job opportunity for many. Eventhough this is less paid, some nurses shift from private sector to Palliative due to both personal and professional reasons. The former is about night shifts, over work, difficulties in balancing with household worksetc. and later concern is regarding professional hierarchy.

c) Volunteers: They are the major work force for the effective functioning of Palliative care. Effective communication and fund raising are the major areas of their work. Volunteers are spread from retired officials, students, house wives, professionals etc. They consider it as a social work and reaching out to patients and community make this Palliative initiative active.

➢ Illness Narration and Patient’s world:

Narration is a way of expression which gives meaning to the experience. I use narration as a theoretical tool to explore lived experience of pain. Clinical use of narratives for therapeutic purpose dates back to the psychoanalysis of Sigmund Freud. Later medical Anthropology made a clear distinction between disease and illness. Klienman (1988) explains illness as what patient experience from the symptoms and its sufferings and it is transformed in to disease when patient conveys it to a practitioner. Thus,illness narrative critiques the dominant practitioner-oriented biomedical definitions and explains patient’s perspective. Illness narrative is the explanation and expression of patients about what they feel, how they understand their states of illness and all together about what they experience. Studies conducted by Young (1955) shows that illness narratives reflect the cultural and social structure and institutionalized ideology and practices. Thus, narratives are used as a representation and a link between individual and society.

There are three kinds of patients in Palliative Care: in-patients who get admitted in IPM, out-patients who receive palliative treatment in clinics and patients who get home care.

a) In-patients:

   Most of the patients are aware of their disease. The major concern about the patient is intensity of physical pain and non-medical worries like financial burden of the family, future of children etc. Lack of social role makes them vulnerable, introvert and passive. They keep talking about their pain and arrange their life cycle based before and after diagnosis of the disease.

b) Out-patients:

   Patients who are referred by other hospitals can register in any of the nearest palliative clinics. Volunteers in a locality create a networking system between patients and doctors which reduce the gap between them. This creates an informal surrounding in these clinics. Free medical service is one of the major reasons for patients to consult these clinics.

c) Home care:

   A team of doctors, nurses, and volunteers from the locality give visit to patients in their home. Most of the patients at terminal stage prefer to stay at home than in hospital setting. Along with that financial crisis, physical disabilities, lack of people to help, limited transport facilities, remoteness of residence etc. makes some patients to prefer be at home. Since these patients need continuous medical attention, family members are trained with basic medical care.

➢ Community Care:

Due to the over medicalization of treatment and cure to patients, health service provided by general clinics is not able to address the major problems. It is mostly affected by the chronic ill patients who requires more than medical intervention. Due to this limitation of existing medical services and the realization that primary care givers like family, friends and volunteers can do a major role for patients, Palliative Care incorporated community service. Thus, Palliative Care is an alternative health care initiative with people’s participation. Palliative Care promotes active community participation at all stages of treatment and rehabilitation.

Patients with incurable and life shortening disease suffer problems other than physical issues. Some of them are anxious about the disease and death, financial crisis due to the large amount expended on treatment, difficulties of access to places where proper treatment is available, social negligence due to stay back from social roles, spiritual problems etc. Medical service usually address physical aspects of the patient's disease and Palliative Care tries to extend its service to social problems with the participation of community. Volunteers are trained to develop communication skills which include facial expression, body language, listening capacity etc., which aims to provide a comfortable space for patients to express what he/she feels about disease, chances to recovery, treatment with doctor, family issues etc.

In Palliative Care, fund is raised from the community. Micro finance model is used in Palliative Care, where donation from individual or institution or organization is collected. Palliative Care in Calicut has some project to collect donation. 'Track We Leave' is a program which aims to broaden the community participation in fund which collect at least Rs. 3/- per day from each person. In Palliative for Student Programme, student volunteers collect money from schools and colleges in any of the week days. Also, in every year, auditing committee discusses the income and expense. In Calicut, donation from the Gulf migrated people helps to meet the expenses of Palliative Care services. Participation of volunteers in fund raising is a remarkable feature in Kerala society.

Experience of pain

Now we need to critically evaluate the content of Palliative Care in practice and evaluates its understanding of embodied experience of pain. This is an attempt to critically evaluate the gap between the philosophical claims of Palliative Care and its practice. Also, it evaluates 'care' as a concept in the domain of Palliative medicine and reflects on the problems with the institutionalization of care in the context of Kerala society. This is an attempt to reflect on the politics of care industry in the commercialized medical scenario.

- Pain narration:

Palliative care uses a graduated scale from 0 to 10 to mark the intensity of pain and it ranges from no pain to maximum pain the patient can imagine. One's experience of pain may be influenced by many other factors like the intensity of earlier pain experienced in life, gender factor where tolerance of pain in life is socially determined, nature of interaction with others suffering from pain etc. Thus, how much one's expression of no pain and maximum pain using this scale reflects subjective experience of patient's pain is problematic. Understanding of experience of pain is also influenced by social and emotional factors. Here, we can see that, Palliative care rests on the idea that physical pain causes social and emotional problems to patients. Subjective experience of pain and its narration will not be understood within this scientific pain scale.

➢ Cultural construction of pain:

Metaphors, local usages, social attitude towards disease etc., which are influenced by culture are some of the factors which contribute to the experience and expression of pain. Influence of social categories like caste, class, gender etc., in defining the experience of the embodied body and pain is not addressed from the patient point of view. The study however understands even though it provides a space for impersonal interaction, cultural influence in the pain expression and its experience of the patients are not addressed in Palliative Care. Use of biomedical tools and vocabulary in Palliative Care to denote the physical pain is a way the replication of biomedical model of disease.

➢ Total care:

Different dimensions of care delivered in Palliative care is analyzed here.

a) Spiritual and religious care:

Spirituality is often interchangeably used with religion. But religion is related with organized institutions under clergyman whereas spirituality is something which is shared between two people. During the formation of Palliative Care, spirituality was differentiated from religion. This secular understanding of spirituality based its engagement with the lived experiences of patients. Here, spirituality is not about one's religion or organized sects or rituals etc., but are a search for meaning to life. Later, religious dimension of the patients is also addressed under spiritual care. Now the practice of spiritual care in Palliative Care shows that religion and spirituality is used interchangeably. Also, spirituality is the least addressed aspect of Palliative Care.

Medical model of spirituality has many problems. Exclusion of religion from spirituality in practice creates problems to patients. This secular model of spirituality is not able to address many of the issues a patient at end stage of life suffers from. For example, if a patient need a religious solace from a clergyman or a space to practice religious rituals etc., this model of spiritual care will not address. For a patient, it may not always need a search for meaning of life but seeks religious expressions. Non-religious spiritual dimension of Palliative Care engages with general views on the meaning of life and death. Here, some questions are raised like whether patients at their vulnerable stage and their family require these spiritual interventions. On the other hand, if religion is added to the spiritual care, the chance of religious bias of the care giver on patient's belief is higher. Miscommunication and unnecessary spiritual interference in to the lives of patients may create problems to them. Thus, the practice of spiritual care is a very problematic side of Palliative Care. Sometimes in practice, morality of the care givers may influence the delivery of spiritual care. Also, institutionalized training for the ways of delivering spiritual care makes the process mechanical which contrasts with the sensitive need of the patients at the end stage of life.

b) Physical care and emotional care:

In Palliative Care model, physical care is provided by the doctor who received Palliative training. Specialists in mental health like clinical psychologist and psychiatrist provides the emotional care to the patients. The division of physical and emotional care itself reflects the Cartesian philosophy. In practice, physical care is given to the patients with chronic illness and patients at terminal stage of disease and emotional care is provided by the specialists to the patients with mental illness. This compartmentalization of disease and specialization in medical profession misses the subjective experience of pain. Embodiment confirms that pain is not just a physical experience, different factors like emotions, socio-cultural and political factors also influence the experience. In practice, Palliative care functions like the biomedical approach to patients and disease.

c) Financial care:

It is very clear that free medicine and free treatment are the major factors which attract most of the people to Palliative Care. Social biography of the patients showed that majority are from lower class. Lack of effective medical care in public health system and unaffordable treatment in private hospitals made them to move to Palliative Care.

d) Problems in the delivery of palliative care:

In practice, Palliative Care is given to patients a terminal illness stage but it is required throughout the disease stage. Palliative Care act as a supporting system to patients but the larger view on disease and death is not changed. From the public health perspective, the ethical position of Palliative Care is to provide a proper health care to larger number of population than to provide best health care to everyone. This over emphasis on expanding to wider society has compromised the quality of care given to patients.

Existing health care systems are hierarchical in nature with knowledge as power. In Palliative Care, also we can see this tendency. The dominance of doctor in decision making and health care process is evident. The active involvement of volunteers in all stages of the process of health care provision can lead to possible loss of confidentiality, privacy, patient autonomy, quality of care etc. Role overlap in community based Palliative Care shows the tendency of volunteers attempting to even do medical professional job without training. This shows the tendency towards a position where medical knowledge gives power and status.

Politics of Palliative care

Care in Palliative care is service oriented. Public good was the intension behind services in health sector by many Government initiatives. In biomedical field, individual interest is the focus of the medical interventions. Palliative Care bridges the gap between these two and attempts to give individual attention to the patients at the cost of community participation which in practice comes out as a social good.

Community participation in Palliative Care provides a network of interacting people. Success story of Palliative Care in Kerala is because of this active community participation. The strategic implementation of Palliative Care service through this network made it a remarkable feature in Kerala context.

All the posters and brochures of palliative clinics introduce palliative care as a humanitarian attempt or as a charitable act. This social initiative can be viewed from two angles. State's withdrawal from the public services like health leads to movements like Palliative Care. Palliative Care proposes an idea that health is a social responsibility. In Kerala, we can see Government policy of Palliative clinics is opened. But this intervention does not mean that it pressurizes Government to increase public expenditure on health or improving infrastructure etc.

Thus, we can say that like many other NGOs, Palliative Care is used as a shield for Government to give up the public responsibilities. Active participation of large number of volunteers especially youth is a sign of people's withdrawal from the institutionalized political parties which reflects a new social consciousness from the public for new initiatives. Even though Palliative Care does not question the existing system both in medical field and social setup, it opens a wider way for social service.

Conclusion

The study examined the point where Palliative Care departs from biomedicine at its theoretical level. We can see the difference at three levels; one, the approach towards patients, second, understanding the disease and death and third, methods of delivering care. Total care in Palliative Care establishes an informal relationship with patients in order to build personal rapport in the doctor-patient relationship unlike biomedical approach. Disease as a social suffering opens the community participation in Palliative Care which extends the biomedical exclusiveness of doctor's role in treatment. Thus, Palliative model of care have a holistic approach to the patient. In this way, Palliative Care proposes an alternative idea of care and treatment within biomedical framework.

In contrast to the theoretical position, Palliative Care in practice complies with Biomedicine in many ways. Compartmentalization of profession in delivering physical and emotional care and the prioritizing physical care over other aspects of care is a replication of biomedicalmodel. Also, the present study points out that the subjective experience of the embodied pain of patients is not addressed as such in Palliative Care. The complexities of embodiment are not unveiled in Palliative Care. Thus, we can say that Palliative Care misses the experiential pain and suffering.

Notes

1. IASP is a Non-Governmental Organisation formed in 1973 with the purpose of scientific research on pain. It is involved in understanding pain and emphasis on policy interventions to prevent and control pain.
2. http://www.who.int/cancer/palliative/definition/en/
3. https://www.nhpco.org/history-hospice-care
4. Official data from Institute of Palliative medicine during the time period of my field work.
5. http://www.instituteofpalliativemedicine.org/index.php

References

Csordas, T. 1990. “Embodiment as a Paradigm for Anthropology”. *Ethos*, 18(1), 5-47.

Foucault, M. 1973. *The Birth of the Clinic*. New York: Pantheon Books.

Goffman, E. 1969. *The Presentation of Self in Everyday Life*. Harmondsworth: Penguine.

Good, B. 1994. *Medicine, Rationality, and Experience*. Cambridge: Cambridge University Press.

Klienman, A. 1998. *The Illness Narrative*. New York: Basic Books.

Merleau-Ponty, M. 1962. *Phenomenology of Perception*. London: Routledge & Kegan Paul.

Scheper-Huges, N., & Lock, M. 1987. “The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology”. *Medical Anthropology* Quarterly, 1(1), 6-41.

Seidler, V. 1994. *Recovering the Self*. London: Routledge.

Shilling, C. 2003. *The Body and Social Theory*. London: Sage Publications.

Turner, B. 1996. *The Body and Society: Explorations in Social Theory*. London: Sage Publications.