

TRAJECTORIES OF CHRONIC PAIN: SEEKING RELIEF, ARTICULATING THE SELF AND NEGOTIATING STIGMA

A sociological study exploring the 'language' of pain

*Dissertation submitted to Jawaharlal Nehru University in partial
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MASTER OF PHILOSOPHY

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CERTIFICATE

This is to certify that the dissertation titled "TRAJECTORIES OF CHRONIC PAIN: SEEKING RELIEF, ARTICULATING THE SELF AND NEGOTIATING STIGMA. A SOCIOLOGICAL STUDY EXPLORING THE 'LANGUAGE' OF PAIN" submitted to Jawaharlal Nehru University, New Delhi by Ms. Pooja Sharma in the partial fulfillment of the requirements for the award of degree of **Master of Philosophy** is an original record of work carried out by her at CSSS/ SSS under our guidance. To the best of our knowledge, the matter embodied in this dissertation is original and has not been submitted for the award of any other degree or diploma either in our or any other university.

We recommend that this dissertation be placed before the examiners for evaluation.

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1. Introduction

“Greek physician Alkmaion: We human beings must die because we have not learnt to connect the end with the beginning again and this is something we can never accomplish.’ This is genuinely disturbing observation for it tells us that it is not something in particular that we lack, but rather everything”

Pain makes and unmakes the everyday world, showing its contingency and lightness.

~R. Kugelmann (1999: 1663-1676)

The term ‘pain’ is derived from the Latin word ‘poena’ which means a fine or a penalty (Good et al: 1994). The present chapter takes into account the existing debates in the field of pain studies within social sciences and attempts to provide a synoptic view of the main arguments that are derived from a critical analysis of those debates. This chapter delineates the research objectives and research questions that are to be considered in the following chapters. The in-depth analysis of chronic pain and its associated issues requires a critical examination of the perspectives derived from multifarious theoretical orientations. The chapter provides an introduction to the theoretical underpinnings behind the conceptualization of chronic pain, and associated issues like its clinical manifestation and its impact on the everyday life of the chronic pain patients. Apart from this, there is a short note on the research methodology and chapterisation of the dissertation. The chapter concludes with a note on justification of the title along with discussing the linkages between the various chapters.

1.1-Chronic Pain: A Conundrum

A critical evaluation of debates on pain, in general, and chronic pain, in particular, helps in locating the significance this topic holds in social sciences, social anthropology and sociology in particular. Chronic pain studies are one of those areas where the ‘other’ of

Another important thing to be noted in, here, is the fact that pain has an attribute of physicality linked to it. Not to be forgotten, what Jackson (1994, 2000, 2011) mentions in her research of more than two decades is the aversive nature of pain. Western scholars have asserted their world view as scientific, rational and modern. Medicine is one of the ground breaking discoveries made by the western world. It is a combination of all the above mentioned three traits which validate medicine in the eyes of society and medical intervention is perceived as the first step towards providing a solution for problems linked to human body, pain being one of them. Thus, the physical or bodily character of pain combined with its aversive nature and the consequent suffering call for a medical recourse.

Moreover, pain in the body is the first symptom of an illness which again indicates the need of medical intervention. The medical intervention apparently promises to provide relief by uprooting the cause of pain. All the above factors lead the patient to explore the available cures and treatments. Western world has been known for its approach towards heavily loaded terms such as rationality and normality which, on the face value, appear neutral. Rationality is an intrinsic aspect of any modern society and is deeply manifested in the western society. Medicine is one branch of knowledge which is seen as rational and is definitely a part of modern western world. Cross culturally as well, the notion of a healthy being implies a sound body and a sound mind. World Health Organization (WHO) too defines health as ‘a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’¹.

If all these factors are taken into consideration, one can have a clear understanding to the first step taken by the sufferer. For the patient, seeking relief tends to be the foremost goal and it is possible by looking for a cure for the problem within the body or at the site of pain. The case of chronic pain creates a problem when either the source of pain is intractable or even after treating the cause, the pain lingers. No sufferer gets to know the exact moment when the pain turns chronic. It happens gradually, thus, leading to loss of

¹ Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948. The Definition has not been amended since 1948.

hope, increasing frustration, and feelings of being a liability on others and self-blame arises. Chronic pain, thus, acts as lens through which questions associated with science and rationality can be evaluated. Alongside, it raises question on the prevailing notions of health, sickness and disease.

Leder (1992: 72- 73) opines that pain asserts itself not only through its characteristic temporality but also through its *sensory intensification* as well its qualitative feel i.e. it hurts. He terms the feature of temporality as *episodic structure* of pain. Chronic pain also has episodic nature and it changes its intensity in accordance with one's activities. He states that chronic pain with no solution grabs the attention with unmatched intensity. The feelings of chronic pain patients about their well being are amorphous in nature with neither having definable beginnings nor abrupt transformations. All these features of chronic pain pose an enormous challenge to the western world and its assertions (which have been often used against the world view of non-western and traditional societies to create a hierarchy of knowledge).

When biomedicine fails to provide cure or even some temporary relief to reduce the suffering, the second step towards seeking relief is a shift from biomedicine to complementary and alternate medicine (CAM) which again has not proven useful in decreasing pain (Good et al: 1994), (Greenhalgh: 2001) and (Jackson: 2000). In the dearth of an efficient health care system, chronic pain patients are left on their own to come to terms with their painful lives. Pain becomes their lived reality and the pain centres which promise to assist the patients end up teaching them coping up mechanisms. Hence, instead of treating pain the goal shifts towards learning about managing pain, encouraging acceptance to this discomforting condition. In a few cases, where patients learn to manage chronic pain, accept it as a part of their everyday life, success is claimed and those who are not able to accept pain are held responsible for their condition. As Morris (1991: 73) says,

“As one medical treatment after another fails, chronic pain becomes an experience about which there is increasingly nothing to say, nothing to hope and nothing to do. It is pure blank suffering.”

Scarry (1985) opines that pain destroys the language. Pain diminishes the ability of pain sufferers to communicate or even conceptualize their pain. The fact that pain is resistant

to language is no accident; indeed, acute or chronic pain can cruelly interfere with communication—even with the ability to speak at all. Sufferers are isolated from those around them by the very fact of their pain, which creates a burden of suffering distinct from the pain itself. This way, pain can have a deleterious impact on personality and on relationships.

Scarry argues that pain is the most absolute definer of reality. For the person in pain, there is no reality besides pain; if it hurts, it must be real. This characteristic of pain makes it useful politically, for instance during torture and war². Hence, pain is more than a medical term. However, the author does not take into account cultural/historical differences in how pain is perceived or used. For all humans at all times, she assumes, pain is the mark of the real, even if that stable characteristic is used for different cultural ends. Morris's (1991:1) work on pain complements Scarry's work. He begins with the objective to "describe how the experience of pain is decisively shaped or modified by individual human minds and by specific human cultures. It explores what we might call the historical, cultural, and psychosocial construction of pain." Contemporary western culture tries to convince us that pain is nothing but an aspect of disease and, therefore, a medical problem. However, pain as a human experience in its chronic form turns the tables and highlighting the loopholes existent in biomedicine and CAM.

² The author cites the case of torture and war, for example, the reality of the one being tortured is reduced to an awareness of pain, while the torturer's world remains fully present. This is realized most emphatically when torture is described as information-gathering. The torturer insists on questions that for the tortured are no longer of any concern.

In the dispute that leads to war, one country's beliefs are pitted against another's. Both sides' are thus called into question; if there is disagreement about the facts, it becomes apparent that the facts are based in opinion, not reality. The injured bodies of war re-connect the victor's beliefs with the material world. If the injured body is the ultimate in reality, the injured bodies of war can be used to signify the reality of the victor's position. Simultaneously, the pain of individuals in war is transferred to inanimate objects or large groups. Thus, one speaks of a particular battalion being wounded or weapons being disabled.

Pain in its chronic form tends to be a problematic category. The category of chronicity was introduced in biomedical language in opposition to one of “acuteness” at the beginning of the twentieth century. The author perceives it as a challenge to biomedicine as sometimes it is difficult to determine when a disorder became chronic. The author states that the concept of chronicity confirms to the impossibility of cure and therefore, poses a challenge to the existential power dynamics associated with biomedicine in a very different manner as compared to the case of acute states which remains very much under the control of biomedicine.

Moreover, the medically unexplained disorders are often interpreted as psychopathology and most of the patients are prone to be labeled as mentally feeble with no problem in their body but in their mind. So as to avoid the tag of having a problem with their minds, sufferers try to express themselves in a language which suits more to the normative biomedical discourse. This again can be reasoned to the dominance of biomedicine in our everyday world. In case of chronic illnesses, even chronic pain, it tends to be extremely difficult to shrug off the labels imposed by institutions, more so in the absence of lesions. Chronic pain patients are always trying to put forth their voice so as to avoid being labeled as malingerers or suffering from something which has to do with the term ‘psycho’, even remotely so. Therefore, the role of language in the lives chronic pain patients becomes significant. The paradox, on the other hand, is that chronic pain patients are constantly struggling to find the language to articulate their suffering and their notion on self.

The everyday life of chronic pain patients is all about painful existence. Something which will not be diminishing with time. After meeting failure at the hands of various health care systems, they are left on their own to understand their suffering as well as their bodies which, by now, seem to be an alienated entity. They are in a constant quest of articulating their notion of self which changes post chronic pain experience. Chronic pain becomes a language in the transforming social relationships of the patients. The present work attempts to look at the language of chronic pain as well as examine it as a language in itself when it comes to the issue of negotiating relationships with those surrounding the patient. The ambivalent status of chronic pain patients is responsible for

an altered selfhood which is vulnerable to stigmatic reactions from others because of a never ending sick role as well. Jackson (2005: 332) calls the chronic pain patients as liminal creatures, as ambiguous beings who are possible threats to the existing social order as they pose a challenge to normal course of biomedical treatment. Chronic pain sufferers are perceived to be entities which have an ambivalent ontological status as their state confuses the principles surrounding the morality of health and sickness.

A significant question emerges from the above discussion which is of utmost importance to the lives of chronic pain patients-pluralistic medicine has not been able to address the concerns of pain sufferers efficiently, what is it that provides an end to the suffering? Is chronic pain to be analyzed using a different intellectual lens? Cultural understanding of pain can be one of the significant measures to ameliorate the suffering of pain patients. It can be asserted from the very fact that chronic pain is not ubiquitous it is limited to particular regions and cultures. This pattern can be questioned again. Another important question arising here is whether to perceive chronic pain as an essentially western phenomenon? Is it to do with the cultural notions that chronic pain remains limited to a particular territory? Or does this correlate with the lack of health measures available across many pockets of the world that chronic pain goes unaccounted for?

Especially in the context of India, one does not find much research on chronic pain research. In case of terminally ill patients suffering from severe pain, there is a dearth of palliative care services. Palliative care which is associated with relieving and preventing the suffering of patients is at a nascent stage in India. This demonstrates a poor state of affairs in case of treatment of chronic pain patients in India. Indian states like Andhra Pradesh³ and Kerala have stepped forward towards adopting new drug regulations and encouraging palliative care respectively. Kerala is the only state in the country providing palliative care in each of its districts⁴. However, rest of the states still have to follow the suit. If this is what the states are offering for terminally ill patients, one can easily understand the plight of chronic pain patients who are not terminally ill.

³ <http://www.hrw.org/en/news/2009/12/17/treatment-patients-chronic-pain-india>

⁴ <http://www.hrw.org/fr/node/86140/section/8>

Against the backdrop of the preceding discussion, this dissertation attempts to examine the arguments raised above at length. The present work does not propose a way out of this conundrum; rather it is an attempt to outline the complexities involved in dealing with various perspectives on chronic pain. The present work attempts to raise some questions regarding chronic pain itself and simultaneously engage with the various issues and perspectives associated with chronic pain in the field of psychology, sociology and anthropology.

1.2-Literature Review

The following review includes the key concepts and approaches around which the arguments are to be formulated vis-a-vis chronic pain. Chronic pain as a research topic incorporates a number of debates beginning from its ambivalent nature and the consequences it, thus, has on the lives of patients. Jackson in her works (2000 and 2011) states that, despite the fact that pain studies range from psychophysics and biomedical engineering all the way to philosophy, psychology and economics, relatively little can be found in the discipline of anthropology and sociology. Still anthropology and sociology can have much to offer with reference to chronic pain. As she (2011) states,

“Yet, given the truism that the best locations for understanding a society are the sites where things don’t work, pain’s invisibility and ontological and epistemic uncertainty offer fertile terrain for anthropological investigation.”

In the present work, not only the anthropological literature but studies in other disciplines like sociology, psychology, philosophy, science and medicine have made their contribution to develop an understanding of chronic pain. The present review will not be able to take an exhaustive overview of the existing or available literature due to feasibility constraints. Rather, it is an attempt to incorporate and examine various perspectives and associated debates on the topic and seek a thematic understanding of the issue.

Baszanger (1989: 425) mentions chronic pain as a prevailing pathology in modern societies. (1998: 51) opines that an upsurge in the cases of chronic illness in the west can be attributed to a decrease in the mortality rates from acute illnesses due to better

health care facilities. Jackson (2011) states that much less work exist with respect to chronic pain and anthropological research in the US. She states that an estimated 86 million Americans have some form of chronic pain and over US \$ 100 billion is spent on treatment related costs and loss of productivity due to chronic pain. Jackson (2011) lays emphasis on anthropological research in the field of pain medicine stating that it would definitely be interesting to look into the relationship of pain medicine with powerful institutions like pharmaceutical industries, insurance companies and the state which, for now, does not form the agenda of the present dissertation.

The understanding of pain in modern societies and in traditional societies is extremely different. Modern world regards pain as a salient feature of nervous system whereas in traditional societies it is perceived as a result of social transgression (Free: 2002). Many anthropologists like Shostak (1981) and Free (2002) have documented and discussed different pain perceptions across the traditional societies. The history of pain literature shows how pain has been a ubiquitous feature of human experience but chronic pain is not ubiquitous. Nor is it known to be universal and cross cultural (Good et al. 1994: 3). Jackson (2000: 202) quotes Bonica and Black who define chronic pain as any continuing pain that has lost its biological function. .

Baszanger (1989: 425) calls chronic illness a multidimensional category possessing three main characteristics of disorganisation, duration and management. The two common characteristics which are mentioned by her are the chronic factor of pain and its management in the clinical institutions which goes on for an indeterminate period of time. Gradually, this pattern disrupts the everyday lives of the sufferers as well. And the management of pain goes beyond the clinical settings. It becomes a part of social life and influences social relationships. Due to the elusive nature of chronic pain, it tends to pose a greater difficulty for the health practitioner's to propose an effective treatment plan to the people suffering from chronic pain.

She states that if one looks into problems associated with pain, chronic pain in the present case, one comes across two themes which are often at cross-roads. The first theme takes into account the relationship between chronic pain and biomedicine, while the second one

focuses on the experiential aspect of chronic pain. This dissertation takes into account both the aspects.

This takes us to an obvious point that pain, especially in its chronic form, is a significant issue not only for medical scientists but for social scientists as well. Medical practitioners and medical research do not act in a social vacuum. Hence, one can look at biomedicine as part of a larger whole, the western culture.⁵ Medical anthropologists like Zborowski, Rivers, Ackerknecht have provided cultural explanations so as to understand pain and pain behaviour which have long been put aside for their superficial claims (Good: 1994). No matter what, chronic pain has a cultural aspect associated to it. Phenomenologists look at body as an existential ground of culture (Csordas: 1990). Jackson (1994: 211) argues that culture can, thus, be seen as a projection of body into the world which implies that the altered self of chronic pain sufferers is also a part of culture and it is the pain which acts as the catalyst responsible for this alteration. This further implies that pain acquires a meaning which is responsible for an altered identity. Hence, while we talk about chronic pain it becomes imperative to see pain as not only a physical sensation with overlays of meaning but as an entity which has meaning, impregnated by culture.

Hilbert (1984) provides a cultural and linguistic explanation to the suffering of chronic pain patients. As per him, pain is not a problem; the problem lies in the culture and language. Jackson (1994: 212) suggests that patients themselves seek physical explanations for their troubles as it provides them with a leeway to their quest for legitimacy as well as to prevent themselves from the trouble of looking for an adequate language to put their suffering to words. Jackson (1994: 210) calls pain as a subjectively meaningful experience because of which it is bound to have a cultural meaning.

Skuladottir and Halldorstir (2008: 891) state that 'pain is not a disease, it is a sensation comparable with the discomfort one experiences from touching hot object or element. As a lived process, again, chronic pain has adverse consequences on the sufferer's entire life

⁵ Medical knowledge has spread out in a universal fashion, the medical practitioners be it in West or in East work on similar lines as their understanding is based on shared scientific knowledge. Still, the doctor-patient interactions are heavily influenced by the cultural settings.

affecting his/ her sense of self, the social relationships and altering the routine course of life.

Across the discipline of medicine, experts have been putting in much effort to look for ways through which the chronic pain patients can be provided relief. As per Klienmann (1988), the subjective and invisible nature of pain has always been observed as raising suspicion that the patients might be malingering. Parsons (1951) 'sick role' talks about the patients' behaviour, in case of sickness, which has to abide by the socially expected ways of conduct in case of any illness. One of the many ways employed to diagnose pain includes methods of measuring pain. This has been widely argued as to who decides that one person's pain is greater or lesser than somebody else's pain. Thus, pain being a relative and extremely subjective experience turns out to be a baffling puzzle for patients and practitioners.

The problem, as seen in case of pain patients, is not only of representation of self but also of the chronic nature of pain. What worsens the situation in many cases is a lack of lesion. But these are some of the extremely intrinsic features of pain. One can never overlook, nor rule out completely, an exterior shrouding the chronic pain patients which is formulated by misdiagnosis. Illich (1975) brought this to the public eye long time ago in his account on iatrogenesis. In addition, the superlative status granted to medical knowledge silences the lay knowledge as well as the category which constitutes alternative medicine. Leder (1992) discusses the flaws in medical thought and practice due to which biomedicine fails to provide permanent relief to pain patients. Leder (1990: 71-79) describes pain as the strongest sensation of our body. It has immense power as it is capable of sidelining other sensations felt by body. It tends to seize the body, it hurts.

"In the face of pain, one's whole being is forcibly reoriented." [Leder (1990: 73)]

Honkasalo (2010) states that in case of chronic pain, the patients' lives observe a double delegitimation. The first being the suffering of chronic illness which has ambiguity as a necessary feature and the second being the invisible aspect of chronic pain which further challenges biomedicine leading to a confused diagnostics. Also, the author opines that chronic illness generates ambiguities for biomedicine as well as in the life-world of the

patient. In case of biomedicine, it attains ambiguity as it lacks definite criteria in terms of cause and function. Also, it is quite difficult to locate the moment when an illness becomes chronic.

Illnesses are lived processes, so is being in pain. Hence, chronic pain just like chronic illnesses touches human lives in more than one ways. It alters identity as well as social relationships. Also, as discussed earlier, chronic pain is always accompanied by numerous approaches to healing. Such a complex web of healing practices leads to multiple interpretations of pain attributing a complex character to pain in its chronic form.

This ambiguous nature of pain as per Honkasalo (2010) makes chronic pain a contested site in the western world where relations of human suffering, power and knowledge come at loggerheads with each other. It tends to be a natural process that whenever we come across ambiguity we try to look for cultural meanings. These cultural logics make us understand the problems which are met with when one is dealing with a complex issue like chronic pain. Cultural logics provide us with an insight towards the processes responsible for the construction of chronic illnesses. It also makes us question the crisis suffered by those sufferers who can never be, in biomedical terms, cured? This is possible by delving deep into the relationship of chronic pain with the notion of self.

As a lived process, chronic pain has adverse consequences on the sufferer's entire life affecting his/ her sense of self, the social relationships and altering the routine course of life. Henceforth, it becomes imperative to review the whole process and understand the mechanisms involving a transition from a normal self to multiple undervalued selves which are often prone to stigma.

The following chapters take into consideration the nuances of altered selfhood and its subsequent repercussions on the sufferers' lives. In these chapters, I propose to discuss what I would like to address as experiential aspect of health and its consequences. Experiential health here implies an embodied experience of one's state of being that derives from the complex relationship between physical, emotional, environmental and socio-cultural components of living.

Pain behavior is another important aspect in the lives of chronic pain patients and it can be verbal or non-verbal. Non-verbal pain behavior comprises of grimaces, whining faces, gnawing and other physical gestures like showing inability to move. Body is an essential tool which can be used to express pain. The notion of self and body is to be understood within the cultural setting. The cultural setting which is being discussed here is that of sufferers and non-sufferers of chronic pain. Csordas (1990) states that the understanding of body is not to be understood with relation to culture, rather it should be seen as a part of culture which implies that body functions as the existential or experiential grounds of culture.

Examining the role of language is important to understand the suffering of chronic pain patients as language forms another important aspect of self. George Herbert Mead (1967) proposes that a whole arena of human social life undergoes a unique experience which can be called "A conscious social language". It is unique for a person because unlike the other communication patterns particularly present in some of the higher forms of animals, the human communication is aided by language. It is the consciously shaped language, therefore, which makes the human communication uniquely social and distinct. Scarry (1985), states that any kind of pain silences the sufferer. The fellow sufferers understand their language. Sufferers feel the need of a cogent articulation of thoughts to attain legitimacy in the everyday world of non-sufferers. Wellard (1998: 51) states that during social interactions with others, the sufferers are constantly asked for an explanation about the difference in their states, their gait, and their eating habits which do not resemble with those of non-sufferers. This is done in the quest of attaining legitimacy, to show that even they are normal and to avoid stigma of not being able to shun the sick role ever. The never ending sick role is uncalled for in the society. There arise conflicting situations where the chronic pain patients start negotiating with themselves regarding the presence of pain in their bodies.

The above mentioned studies indicate the impact of chronic pain on the sufferers' lives. Alongside, these studies also show the multiple issues associated with chronic pain which make it an important concern towards alleviating human suffering.

1.3-Research Objectives

Pain as a conceptual category has been interpreted in more than one way across a range of disciplines. This dissertation deals with a particular type of pain category, referred to as 'chronic pain'. The central objective of the present work is to explore the underlying suppositions and interests which make chronic pain a questionable category in the light of multiple perspectives. In addition, the dissertation attempts to understand the manner in which chronic pain is enacted within the conventional medicine in anticipation for the status of 'disease- like entity'. The dissertation also attempts to observe and critically examine various approaches being used to find relief from pain or negotiating with one's self to accept it as a part of life.

1.4-Research Questions

The study of chronic pain gives rise to many fundamental questions like what are the factors which problematise pain in its chronic form. Why does pain in its chronic form generates interests among researchers? The study of chronic pain also gives rise to questions associated with role of culture, gender, science and expert-lay divide which are significant for an intricate understanding of this issue.

Another significant question which comes up during the course of research on chronic pain is about role of biomedicine in providing relief. In majority of the cases, despite providing no respite to the sufferers exorbitant funds are spent on the treatment related costs. Here it becomes crucial to question the dominant voice of biomedical discourse in everyday life. This also raises questions associated to the notion of body and associated discomfort especially in the western culture. This requires an exploration of notions regarding body, well being, cure and treatment.

In addition, the question related to care of the sufferers and the way the concept of self management is introduced into the patients' lives and its possible repercussions becomes important. What kind of negotiation is done by the patient to accept pain as a part of self? How efficacious is this approach in case of coping up with the suffering? The

chronic pain condition disrupts the social order. It alters the notion of normalcy in the lives of patients. If chronic pain is all about management (which implies acceptance) and seeking care, what kind of notion of normalcy do the patients end up acquiring and how universal is it in nature? Can this altered state of normalcy attain validation in the world of non-suffers and if not what can be its possible repercussions? This requires examination of aspects like language of chronic pain sufferers and the culture they are a part of. In addition, most of the pain studies demonstrate a constant struggle a patient undergoes to grapple with a condition which greatly hampers his/her ability to put his/her pain into words. This creates a paradox which can be examined by looking into the issues related to the notion of body and the self, the questions associated with identity and meaning.

Since the suffering, in case of chronic pain, has to do not only with physical discomfort but also other aspects like social relationships, anticipating validation of one's condition by experts, altered sense of self and the fear of getting stigmatised, it becomes pertinent to explore how sociological and anthropological approaches have constructed the notion of self. The pain question is often raised in terms of looking at it as a sensation and negating it as an emotion or vice versa. This becomes essential to look if this dual nature of pain, as a sensation and an emotion, tends to be problematic especially in case of chronic pain. In addition, the stigma associated with chronic illness and the resultant changes in the life world of chronic pain patients, who end up being not only patients but sufferers as well, makes us question if there is a leeway out for the sufferers to lead a life of respect without getting stigmatised. The purpose is not to look for an answer but look for probabilities which can make it possible. How feasible is this argument in the first place? And in case it has no answers for now, are the pain patients supposed to suffer at the hands of medicine, society and their own inner conflicting selves?

Also, a very striking fact which was observed during the course of literature review is the prominence of concern for chronic pain in the west [in 'Anglophone society' as mentions Menges (1994: 872) in the findings of research conducted on chronically ill patients in Norway], this raises the question of values associated with health and well being in the west.

1.5-Research Methodology

The present work is entirely based on the analysis of secondary literature from diverse fields of study like medical philosophy, medical history, sociology, psychology and social anthropology. Pain is often studied across the disciplines and there are many lines of thought arising from different schools of thought within those disciplines. The present body of work follows deductive approach as arguments are derived from the generalizations rendered in the secondary sources. The secondary sources primarily comprised of online journals available through online databases (like JSTOR, Science Direct etc.), library facilities (especially services like DELNET which made it easier to get the desired books from any part of the country), newspapers and literature available online in discussion forums, articles, blogs, reports from the website of WHO (World Health Organisation), IASP (International Association for the Study of Pain) and Pallium India. Two of the most significant works [Jackson (2000) and Greenhalgh (2001)] on pain which helped me formulate the framework of this dissertation were provided to me by my supervisor, Dr. Harish Naraindas. Another important article, which was under publication (then), by Jackson (2011), was provided by the author herself through email. Much assistance was taken from other online sources and the details regarding the respective websites have been provided in the bibliography. The work also tries to incorporate a sensitive approach by taking into consideration short documentaries on pain.⁶

1.6-Theoretical Orientations

The examination of chronic pain in this work is constituted by discourses about pain itself; i.e. about the meaning and the way it is practiced/ enacted in clinical institutions. The present work does not provide us with any conclusive answers. Chronic pain, when understood from medical or psychological perspective, looks for explanations within the nervous system and nerve stimuli, where as if observed from the perspective of social

⁶The following link was obtained from the website of IASP. It takes us to a series of short films which can be watched online or ordered. These films are themed around pain control and other sensitive issues pertaining to hospice care as well. <http://www.lifebeforedeath.com/movie/short-films.shtml>

sciences, more heed is paid to the experiential aspect-to the suffering of the patients and the changes brought in everyday life of the sufferer.

The present work is consistent with a paradigm where the focus lies on revealing relational, processual as well as historical features of chronic pain. This dissertation is also influenced by the phenomenological understanding of chronic pain and takes into account the embodiment paradigm to have a deeper understanding of questions associated with body and self. The analysis of embodied experience in this study is informed by works of Bourdieu (1977), Douglas (1966), Turner (1969), Leder (1990, 1992), Strathern (1996), Scheper-Hughes and Lock (1987), Jackson (2011) and Csordas (1990, 1994) who emphasize the use of body as a canvas on which social codes of conduct are inscribed and through which the social conditions are subjectivized as bodily experiences. In the present work, while discussing chronic pain, patients as stigmatized individuals have been seen by many anthropologists as liminal entities.

The concept of embodiment comes up in psychological anthropology and leans towards phenomenology and has been elaborated lucidly by Thomas Csordas (1990). Another concept used, in particular, to elaborate stigma is of liminality. In anthropology 'liminality' is primarily a phase of a ritual, whereas liminality in a medical context is a major category of the experience of illness. Liminality was first used in anthropology by Arnold van Gennep, in 1909, in his study of rites of passage. Victor Turner (1967, 1969) elaborated on the term liminal, and applied liminality to ritual, drama and performance (Turner,1979), which he explored as public liminality and defined it as a space between and betwixt the normal, day to day cultural and social life – a particular space, which serves to reverse individual roles or social status. Turner (1969, 1979) saw liminal as a stage in transition. Liminality pertains to a stage in the process of change, a stage of threshold (*limen*) that alludes to the possibility of moving to a new stage or reverting back to the old. In Turner's words, "coincidence of opposite processes and notions in a single representation characterizes the peculiar unity of the liminal: that which is neither this nor that and yet is both" (1969:95). The idea of liminality has been productively used in understanding the state of illness, for instance, chronic pain and its sufferers as liminal entities (Jackson 2005) and Honkasalo (2010). In these studies,

liminality is seen in disruption, disintegration, separation, ambivalence of categories and roles, suspension of norms, exclusion, and imputation of pollution or dangerousness.

Another significant concept to be used implicitly though out the work is about the mind/body interaction and its association with chronic pain. Jackson (2005: 343) cites Kirmayer (1988: 83) states that 'mind-body is so basic to Western culture that holistic or psychomatic approaches are assimilated to it rather than resulting in any reform of practice. Distress is dichotomized into physical and mental, real and imaginary, accident and moral choice. The duality of mind and body expresses a tension between the unlimited world of thought and the finitude of bodily life. It provides a metaphoric basis of thinking about social responsibility and individual will'. Jackson (2000: 46, 170) perceives this interaction as a key puzzle to the lives of chronic pain patients.

1.7-Chapterisation

The present work is an inquiry into three key themes associated with chronic pain. Chronic pain challenges biomedical thought and practice, the notion of scientific and rational. Chronic pain as a concept raises concern for the eventual stigma faced by the sufferers and the altered notion of self. Pain researchers have shown in their accounts that pain experience is more of a journey of an individual which starts from an unsuccessful attempt of looking for relief through medical intervention, failing which it ventures into CAMS. In case, the sufferer comes to terms with the pain as a normal attribute of life, he/she can be at peace. Otherwise, one observes a constant tiff between one's notion of self and one's own body. The situation also makes the sufferer prone to possible stigma because of not being able to shun the sick role. Apart from the introduction, which forms the first chapter of this dissertation, and conclusion, which is the last chapter, this dissertation comprises of three chapters on the above mentioned themes.

The first part of the present body of work looks into the world of pain treatment which actually is not about treating pain but managing it, as will be shown later. This section observes an extended discussion covering multifarious aspects of pain and biomedicine which includes issues like drug dependency, the role of ethnicity, gender issues as

addressed in medical practice etc. The present work widely takes the west as a point of reference while looking into above mentioned issues. This section raises serious concerns regarding the cultural conditioning of a population group in terms of coping with pain and the general societal notion of a healthy being. Also, it looks at biomedicine as a cultural system which because of its scientific temper fails completely to address exactly what it promises to resolve and thus raises a monstrous paradox. And in most of the cases, as is observed in many researches, it leads to a transformation of sufferer's conception of self after inhabiting a pain-full body for long.

The second chapter examines the implications of lived reality of chronic pain on the sense of self. Patients seek meaning for their pain. And while searching for this meaning they articulate a different self for themselves. Jackson (2000: 168) finds out that in many cases, people learn to live with pain by accepting their condition. This, in case of Jackson's work, was possible due to patients agreeing to comply by the therapy provided to them at the pain centre. However, as the author puts forth a patient's concern, if the therapy doesn't work and it gets impossible to bear pain one finally ends up having an exaggerated sense of failure and thereby, shame. The un-ending pain post treatment/therapeutic interventions, is very much liable to be perceived as fictitious and this raises a plausible possibility for stigmatised self-hood.

The third chapter in this dissertation delves deeper into the notion of stigma, which was discussed in detail by Erving Goffman for the first time. Goffman's (1963) notion of stigma was associated with visible aspects. The line of difference in case of chronic pain patients, as Jackson (1994) and Honkasalo (2010) suggest is that something (pain) which is invisible and felt by almost everyone is stigmatized in its chronic form. And hence, it becomes imperative to look for factors which bring in stigma. Also, it is interesting to see the role of stigma in the lives of chronic pain patients and their ever conflicting worlds. This chapter looks into the aspects of chronic pain which bring shame to the everyday life world of patients, thereby adding to their suffering and most importantly making them vulnerable to stigma associated with chronic illnesses.

The title of the dissertation, i.e. "Trajectories of Chronic Pain: Seeking Relief, Articulating the Self and Negotiating Stigma" derives its origin from Brodwin's (1994:

91) work, who while explicating the dialectics of pain and performance begins with the distinction between course and trajectory of an illness. The course of sickness is defined as its physiological unfolding while the trajectory of an illness is the social unfolding of an illness. The title indicates the journey of chronic pain patients beginning from seeking relief to a point where they are left to manage and cope up with this condition for long years, even a lifetime and finally, getting stigmatised for not being able to get rid of their sick role. The subsequent chapters examine and evaluate chronic pain as a concept as well as locate the premises which make it a problematic category.

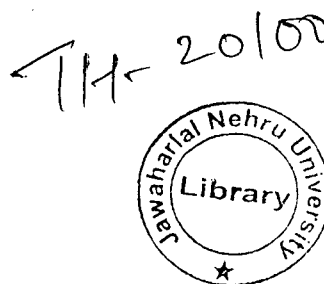
2. Chronic Pain and Medical Pluralism : Finding Cure, Care and Treatment

The first thought which comes to mind when we talk of pain is strangely 'medical' (Morris 1991: 2). This does not appear strange to us primarily because of the dominance of biomedicine in our everyday lives. Western world is industrial and technocratic. These 'modern' influences have convinced the western world that pain is medical in its essence and hence, the first thoughts to colour the mind are truly medical in their essence. Getting rid of pain makes us conjure up a scene which includes doctors, medicines, hospitals, laboratories, drugs, surgery, even insurance. Doctors, whom Morris (ibid: 2) calls the representatives of modern healthcare, play a significant role in cultural construction of pain as the scientific worldview of medicine dominates our society. In the light of the above fact, it is not wrong to say that biomedicine, for majority of population, comes as the first possibly efficient option which can make chronic pain patients get rid of their pain and the associated suffering.

This chapter looks at biomedicine as the first step towards seeking relief in the lives of chronic pain patients and thereby, tries to locate the reasons which are responsible for making the pain patients revert to themselves, as will be seen in following chapters.

Chronic Pain is considered to be one of the most frequent reasons for disability within United States of America (USA) and the estimated count of people suffering from chronic pain crosses the mark of ninety seven million.⁷ Free (2002: 143), in her work dealing with cross-cultural conception of pain and its control, states that pain is the most frequent complaint one observes in North America. Jackson (2011) states that 'pain, especially chronic pain, is a hugely important issue: 40 percent of patients seeking medical attention cite pain as the reason; approximately 45 percent of people will experience chronic pain at some point during their lives; an estimated 86 million Americans have some form of chronic pain and over US \$100 billion is spent yearly in

⁷ Good et al (1994) and Jackson (2000)



treatment-related costs and lost-work productivity due to chronic pain'. With such a huge amount being spent every year, one ponders what biomedicine and other alternate health systems have to offer to chronic pain patients who never get rid of it. In developing nations like India where chronic pain research comes as an entity unheard of this divide raises a few questions like, is it because of the different world views with regard to pain? What makes chronic pain a crucial issue to be probed with enormous amount of money being spent in the west? The answers for such questions are beyond the scope of the present work. For now, it is important to look at the factors which are responsible for the inability of biomedicine to provide relief to chronic pain patients.

Biomedicine, as a body of knowledge, derives its basis from Cartesian mind-body dualism. Also, the biomedical view of body wherein the body is considered as machine poses problems when it comes to understanding a problem like chronic pain (Leder 1992). The key to the identification, treatment and cure of disease has been held to lie in understanding the functioning of the body. For a more clear understanding of the same, it becomes important to look into the history of biomedical thought and practice and, then, correlate it with the problems which emerge when biomedicine tries to deal with chronic pain.

2.1-Chronic Pain and the History of Biomedical Thought

The narrative of chronic pain patients incorporates anguish, frustration, alienation, and extreme desperation to seek all possible recourses that can relieve them from their pain.⁸ Most of the pain researchers in the field of social sciences have agreed upon the hegemony of orthodox medicine when it comes to seeking cure for chronic pain conditions. For instance, Jackson (2000) in her ethnography of pain observes that 'the clinical perspective is the most authoritative discourse, we have, so much so that other ways of talking about pain are almost automatically considered secondary or even suspect'. In addition, she observes that even biomedicine is not able to provide any treatment per se. Instead, it tries to teach patients about pain management. Her ethnography on chronic pain patients is a point in case where 'accepting and coming to

⁸ One comes across this analysis by reading literature on the experiences of pain patients. In almost every text mentioned in reference list, there has been a mention of all the feelings mentioned above.

terms' with the pain has been highlighted as the first and most significant step towards the treatment (which apparently never arrives in many cases) process.

Good et al (1994) see the status of chronic pain within biomedicine as one shrouded within the layers of ambiguity and uncertainty. As per them, the whole concept of chronic pain has been defined so poorly that it ends up having no mention in the standard biomedical taxonomy. There are umpteen reasons for the anomalous status of chronic pain within biomedicine. So as to solve the conundrum and look for reasons for the failure of biomedicine in case of chronic pain, one needs to delve deeper into various epistemologies which guide the thought and practice within the discipline of medicine. The notion of body operative in biomedicine is afflicted with a partial understanding which looks at body in isolation. In addition, citing the works of Rene Descartes, Leder (1992) adds that the knowledge base of modern medicine is mainly established upon the dead or inanimate body. This can be located to his understanding of human body through the dissection of cadavers. Before linking up the complexities involved in the diagnoses and treatment of chronic pain to the conventional medical thought, it is essential to look into the history of medical thought and practice as well as the notion of body as understood within the Cartesian framework.

“The pain is seldom adequately accounted for by the physiological lesions; its course and outcome do not conform to any biomedical or mechanical process. [...]” (Good 1994: 4)

The Cartesian notion of embodiment looks at the human body in an extremely dehumanized fashion, bringing in the mind-body dichotomy. This view has influenced the western world in more than one ways. Particularly, in medicine, its roots are deeply embedded. To begin with, the world view operative in orthodox medicine primarily focuses on ‘the notion of body’ (Leder 1992). Human body has captured the imagination of intellectuals across the disciplines be it philosophy, political science, medicine, sociology, anthropology or literature.⁹ In the predominant medical discourse, the body and bodily symptoms are seen as tools for articulation and expression of pain.

⁹ For more on body read Strathern (1996), Leder (1992), (1990), Csordas (1990)

“Patient body is inherently disorderly and chaotic. It comes to the clinician not as a neat collection of diseases, but as a tangle of aches and pains, complaints and cries, in which past and present are jumbled up together”. (Greenhalgh 2001:31)

Leder (1992) states that in medical practice many assumptions regarding discourses and practices are taken for granted. These assumptions are concerned with disease and related entities and modes of proper treatment. So as to understand those entities one needs to understand the world view as assumed by the orthodox medicine. This world view, as being discussed above, is based on the Cartesian notion of body. Descartes’s, also known as the father of modern scientific medicine, fascination with automatons and the time he had spent (11 years) on conducting dissection of dead bodies gave shape to his scientific explorations as well as his methodology and metaphysics.¹⁰ Foucault (1975:166) acknowledges Cartesian premise based on lifeless body while discussing the growth of medical technology in his account on history of medicine and cites the corpse and the influence of ‘ontology of death’ as the nodal point for this dramatic change. He (ibid. 166) states that,

“that which hides and envelopes, the curtain of night over truth, is, paradoxically, life; and death, on the contrary opens up to the light of day the black coffer of the body”.

According to Leder (1992), Descartes states that *the living body can be treated as essentially no different from machine*. For any good doctor, understanding the ‘patient as person’ dimension is important. Still ‘the dominant thrust of modern medical therapeutics has been upon mechanistic interventions’. This leads to the central paradox in medical thought and practice because a machine doesn’t experience the way a living body does.

“... the machine-model of the body has given rise not only to therapeutic triumphs but to limitations and distortions in medical practice... after all. A machine does not experience, does not inhabit an “existential world”. When it misperforms, this can be explained with exclusive reference to mechanical forces. Not so in human disease and the response to treatment. Here experiential factors play a huge part-- emotions, desires... [...]” (ibid: 23)

The repercussions, as the author states, come to the fore in the form of futile doctor-patient encounters. Medicine’s ability to address patient concerns in a humanized fashion

¹⁰ For more on this see Foucault (1975) and Leder (1992)

is deeply hampered by this mechanistic approach, where in, human body is seen as a conglomeration of parts, defective and functional, while overlooking fears, questions, desires and pains! Thus, chronic pain, an already ambiguous phenomenon which baffles the medics all over the world, when characterized by absence of lesion becomes a state which lies at the middle of sensory and emotional experiences.

But to think of western thought being completely influenced by Cartesian dualism is an exaggeration in itself. Strathern (1996) locates the mind-body dualism in a historical philosophical context wherein Cartesian thought is one of the many within European cultural history. The author (ibid.) compares, for example, fifth century B.C. Greek theories of the "mindful body" to those of the Wiru people of Papua New Guinea, finding in both sets of theories the concept that a form of mind or will is inherent in the body's limbs and organs, including the genitals, so that a woman's vagina and man's penis, for instance, have their own "minds" and are almost actors on their own behalf (p. 53). For Homeric Greeks, too, the author (ibid.) shows how thought, feelings, and the body were crucially connected. Despite these disclosures one can never rule out the overwhelming domination Descartes notion commands in the theories about body and medical science (which has body as its point of reference is no exception to this rule). However, the failure of biomedicine in case of providing relief to chronic pain patients cannot be reasoned completely to its underlying theoretical foundations.

As observed across the literature on chronic pain, the medical model that pervades clinical practice is completely based on mind-body dualism. Sullivan (1986 : 331-350) presents a historical analysis of Descartes' notion of mind body duality and discovers that medicine does pursue certain Cartesian goals, most notably the discovery and utilization of a means of knowing disease that does not depend upon the candor of patients. But it does not employ Cartesian means to 'achieve' this. Further, he proposes that the relevant dualism in case of contemporary medicine is not the mind-body but that of disease and illness. So as to overcome the limitations of this dualism, medicine must rediscover the sentience of its patients through renewed attention to the host factors relevant to the healing and knowing of sickness.

The present work takes into account various vignettes from the ethnographies of pain and other literature on chronic pain to see how those seeking relief from chronic pain conditions get entangled within the complex of hierarchies coming to fore because of the way scientific knowledge and gender is practiced in various clinical institutions and thereby, end up becoming a part of a larger whole which comprises of complementary and alternative medicine too. Also, there are other associated aspects in the case of chronic pain patients like pain and palliative care, significance of pain, the language of pain, medicalisation of chronic pain, opioid dependency, medicine as science, cultural notions or the role of ethnicity in the case of chronic pain and medical pluralism. The present work discusses a few of these associated features to formulate chronic pain problematique. The study of chronic pain engages with three key themes; the role of biomedicine, the altered notion of self and the process of stigmatisation. The very first theme observes a critical analysis of conventional biomedicine, CAM therapies and chronic pain. Themes like women in chronic pain, medicine as a science and significance of pain for practitioners' have also been covered here.

2.2-Pain from the Gendered Lens

Werner et al (2004) while conducting their research on women suffering from chronic muscular pain find out that the accounts of suffering in case of Chronic pain patients comprise of issues related to altered sense of self and shame. These issues are often part of cultural discourses of gender and disease. The authors state that in various studies on pain, the women patients have reported negative experiences during medical encounters.

“They (women) repeatedly find themselves being questioned and judged either to be not ill, suffering from an imaginary illness or given a psychiatric label (Garro, 1992; Jackson, 1992; Johannson, Hamberg, Lindgern, & Westman, 1996; Lilleaas, 1995; Lillrank, 2003; Ware, 1992; Asbring & Narvanen, 2002). Their stories illustrated how they struggled for self esteem or dignity as patients and as women. [....]” (Werner et al; 2004, 1036)

Greenhalgh (2001) states in her work that women seeking treatment for chronic pain is a double whammy. Medicine dominates the patient say due to lay expert divide and on top of that a patient being a woman deepens the hierarchies. Jackson (2000: 145) states that a major part of the discourse on pain in America is concerned with “pain threshold”. The

cultural construction of healthy self challenges the painful self to grapple with the morally superior identity laden by the American value system. Jackson mentions it very carefully that the above concept is usually couched in normal terms, having “low threshold of pain” often implies that one is less matured, strong and in some contexts ‘manly’.

Historically if one tries to figure out the reasons behind the vulnerable status of women’s account of suffering, one finds the notions associated with hysteria. Werner et al (2004; 1037) state that although hysteria has also been registered in men but the relation between hysteria and women body has been striking. They cite Johannisson (2001; 100) who states that at the beginning of 19th century, ‘the diagnosis of hysteria manifested the very horizon of expectation to femininity and the woman: She was seen as (needing to be) ‘sickly, weak, and delicate’. This association has implication on male patients’ pain behavior as well. Werner et al (2004; 1043) find out that in many researches carried out on men suffering from fibromyalgia, it has been observed men do not communicate their feelings spontaneously and find it extremely difficult to cope up with pain in comparison to women as they are ‘reluctant to be given a medical diagnosis which indicates a psychological problem and points to a ‘woman’s disease’.

Greenhalgh (2001: 137) in her personal account of a chronic illness states that despite the fact that “biomedicine is a powerful apparatus of cognitive and social control; it could not have done the damage that was to be done to the patient’s body and mind. It was the combination of biomedicine and gender that was so deadly.” The author in her account states that how being a part of mainstream i.e. white, middle class, heterosexual woman, she had internalized the norms of femininity which taught her to be compliant, since early childhood. During her scholar days, she ended up shunning femininity for feminism. However, after engaging in long conversations with her doctor, even her education (she is a doctorate) could not help her initially to assert her critical self. Her account gives an impression that she considered herself at an equal platform to the doctor when it came to their academic qualifications. She silenced her critical self, but later realised the need to voice her resent.

There have been many researches on chronic pain and gender and it has been reported that women complain more of pain. For instance, Skuladottir and Halldorsdottir (2008) quote Stones (2000) in their work stating that ‘women experience pain (not chronic in this case) as part of their normal reproductive life and they are subjected to whole range of pathological conditions and syndromes of genital origin that cause pain. However, most of these conditions have no direct counterpart in men.’

Many social scientists have carried out studies, time and again, which show the prevalence of pain is higher amongst women in comparison to men; women are more likely to sense pain and women’s pain are classified as medically unexplained disorders more often than men (ibid). The reasons cited for above mentioned claims are observed in the form of an existing ‘cultural lag’ in western societies with women being active at the workforce as well as at the domestic front. However, it has been researched that men’s contribution towards domestic front is depressingly less which leads to stressed and strained bodies eventually leading to chronic pain.

This theorisation does not sound appealing, as in case of women in India, where the women belonging to urban middle class come across similar situations with an upsurge in employment statistics. Otherwise too, the participation of women in the unorganised sector (which usually goes unrecorded) as well as women from hilly regions has always been like what west has been observing only recently. There are however, no studies relating pain to gender or on chronic pain patients in Indian context to compare the claims of the above mentioned research work.

Also, as Werner et al (2004; 1041) quote from Haug’s (1992) theory

“we may assume that the act of ‘saying’ pain in the genre of complaints (Kugelmann, 1999) would be interpreted differently, depending on gender and disease. Women who talk too much about their illness might be in danger of having their complaints interpreted as groundless suffering from unreal pain caused by their inappropriate or maladaptive way of relating to their bodies and health disorders (Werner et al., 2003)”

2.3-Chronic Pain and Medicine as Science

Medical philosophers' like Canguilhem (1989) argue that the most important task for a cultural analysis of science is to unearth how a particular science practice constructs its object of enquiry. He reasons that for biomedicine, at best only a partial science, the construction must start by distinguishing the normal from the pathological. In his formulation, this distinction reflects two conditions: the norms that the dominant social group establishes to evaluate and, therefore, control behaviour, and also the vital condition of abnormality in the biological processes that participate in experience. Thus, for Canguilhem, the question of disease/ illness is simultaneously a violation of the normative (the moral structure of the society) as well as of the normal (the enfolding of that socio-moral structure into the body of individual—its embodiment) the dialectical processes mediating the socially normative and the biologically normal are, for Canguilhem, the ontological and epistemological grounds for understanding health and disease. Chronic pain as an object of inquiry for biomedicine can be understood from this very perspective.

Cassell (2004) states that medicine is considered as a science (as per him his usage of the term science is extremely restricted i.e. modern usage as a branch of study that relates to the phenomenon of the material universe and their laws). He opines that the development of science in contemporary times and the subsequent benchmarks it has set has led to a widely held and crippling prejudice that no knowledge is real unless it is scientific – objective and measurable. From this perspective suffering and its dominion in the sick person are themselves unreal (ibid. viii).

Science goes by the rule of experiment, observation and inference. Rationality and reason are linked to science and the notions which do not fit into the western conception of rationality are considered to be a part of traditional societies. Biomedicine is a western construct and any ailment or pain which persists without any lesions and is chronic, becomes a grey area. Jackson (2000: 37) states that the invisible character of pain presents a serious problem to the practitioners as well as those around the patient. In the pain centres, for instance where Jackson conducted her fieldwork, treating the pain is not important. These centres teach the patients to manage their pain, to learn to live with it

and appear to be interdisciplinary in nature as can be made out from Jackson's account. Expressing pain is a crucial part of pain behaviour and those who fail to exhibit pain in the name of 'suffering with dignity' find it hard to assert themselves (ibid).

The above mentioned reasons have further mitigated the voices of all those who lie outside the domain of science, for instance social scientists, alternative health practitioners etc. These structural hierarchies effect the validation of chronic pain as well as the patients experience in the name of subjectivities. In the lack of such a validation and hence no relief either, patients try to look for treatments outside the orthodox medicine. Another reason for shifting to heterodoxy as told by patients to Jackson (2000: 37) during her yearlong fieldwork in a patient centre was the constant demoralization they met with at the hands of the doctors when told about no 'visible' symptoms leading to their painful condition. The whole experience of being negated leads to an overtly conscious self which fears being labelled crazy. This leads to anxiety also and hence, many of the pain patients, as the author opines, pursued alternate or 'rather bizarre' treatments (ibid).

2.4-Chronic Pain and Complementary and Alternate Medicine

Medical pluralism implies plurality of systems of healing. Especially in the case of chronic pain patients one observes a phase which begins from biomedicine and due to lack of relief moves on to other alternate systems of medicine anticipating relief (Jackson, 2011). This shift is not as easy as it sounds because of the dominance of biomedicine in the lives of people. In most of the cases though, biomedicines dominance does not go away easily as states Bates et al (1997: 1440),

“Anglo-American's general acceptance of biomedical world view of the body as a machine-like entity separate from the mind has also led to problems with the providers when biomedical procedures have failed to bring desired results. Because many Anglo-Americans have accepted the legitimacy and effectiveness of biomedicine, if medical treatments have proved effective, member of this group often become extremely angry at individual providers unable to effectively repair the body and free it of pain. However, this anger has not, for most part, led to abandoning biomedicine in general, but rather to continuing the quest for the one biomedical physician who would finally find and fix the mechanical problem the patient believed to be causing his or her pain.”

With biomedicine offering least help, chronic pain patients try to look for other recourses to get rid of their pain like CAM i.e. Complimentary and Alternate Medicine. The World Health Organization has defined CAM as “a broad set of health practices that are not part of a country’s own tradition, or not integrated into its dominant health care system”. Complementary medicine is used together with conventional medicine, and alternative medicine is used in place of conventional medicine. As such the definition of what is alternative or complementary may vary by country. As per Jackson (ibid: 29), the staff at CPC (the pain centre where she conducted the fieldwork) was more welcoming towards alternative therapies while the senior doctor i.e. the doctor in charge was unaware of these therapies being carried out by his staff members as they believed him to be too much in favour of ‘his style’.

“... he is very attached to his mode of interaction with patients, which is, of course, the confrontative style and really rarely even acknowledges some of the other people who are doing more alternative sorts of things with the patients... [...]” (ibid.)

Jackson (2000) states that the staff at the center saw holistic medicine as a larger picture where one observes the entire life rather than a particular organ or body part and looked for mind-body healing rather than depending on orthodox medicine only. According to a study in the Journal of the American Medical Association, 40% of Americans and more than two-thirds of the world population use complementary or alternative therapies. CAM (Complimentary and Alternate Medicine) as defined by the Evidence Report (Feb, 2009),

“CAM is comprised of a group of therapies that are considered to be outside the scope of treatment of most conventional practitioners or therapies. The number of therapies and practitioners classified as CAM can vary depending on the country, but a recent classification scheme has been established within the U.S. These CAM therapies represent diverse health system approaches, health practices, and products that are not presently considered to be conventional. Conventional medicine in the U.S. is practiced by medical doctors, osteopathic doctors, physical therapists, psychologists and registered nurses. However, osteopathic physicians do practice osteopathic manipulative therapy which can also be considered CAM in nature. This raises the issue that an increasing number of conventional practitioners are including what have been traditionally categorized as CAM therapies in their current clinical practice. There is some confusion as to whether the practitioner or the therapy should be the basis upon which the treatment is classified as alternative or complementary or conventional.”

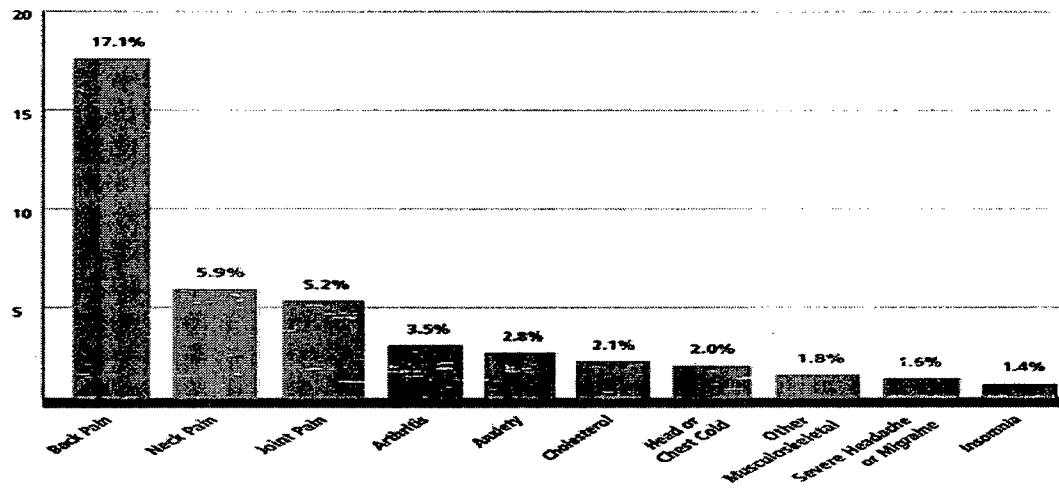
Chronic pains pose a high financial burden on national exchequer in United States as the relief for chronic pain is a public health concern in US (the country).

“Back related pain has a high morbidity and cost burden in the United States (U.S.) and other industrialized countries. Treatment for this pain can be multidimensional and include conventional care, complementary and alternative medicines (CAM), or both. CAM is comprised of a group of therapies that are considered to be outside the scope of treatment of most conventional practitioners or therapies. The large constellation of treatment modalities that constitute CAM are used widely throughout the U.S. and internationally, both by individuals who are healthy and those who have specific health concerns such as back pain. Use of CAM therapies can include visits to specific practitioners, as well as self-treatment (for example, when using herbal products, or relaxation techniques)...” (National Center for Complementary and Alternative Medicine. (2007, February).

Practitioners of complementary medicine, such as acupuncturists, chiropractors, and naturopaths, often view health as a balance of physical, emotional and spiritual factors. Complementary treatment often attempts to restore that balance. The most widely used complementary medicine practices in the United States are osteopathy, acupuncture, chiropractic, homeopathy, naturopathy, and herbal medicine. Since 1990, Americans have increased their use of such therapies by 30% and have paid \$27 billion in out-of-pocket expenses. Renzhofer (2010: 4) in her thesis on medicalisation of chronic back pain records that patients are usually dissatisfied with biomedicine as it leaves them ‘over-medicated, drug dependent and under the knife’. Another of her finding shows that when it comes to CAM treatments, both patients and physicians have concerns about its efficacy. Following table shows the types of diseases (majority related to chronic bodily pains) for which CAM is used:

Graph1. Disease / Conditions for Which CAM Is Most Frequently Used Among Adults- 2007

Diseases/Conditions for Which CAM Is Most Frequently Used Among Adults - 2007



Source: Barnes PM, Bloom B, Nahin R. CDC National Health Statistics Report #12. Complementary and Alternative Medicine Use Among Adults and Children: United States, 2007. December 2008.

▪ Source; Barnes PM, Bloom B, Nahin R. CDC National Health Statistics Report # 12. Complementary and Alternative Medicine Use Among Adults and Children: United States, 2007. December 2008.

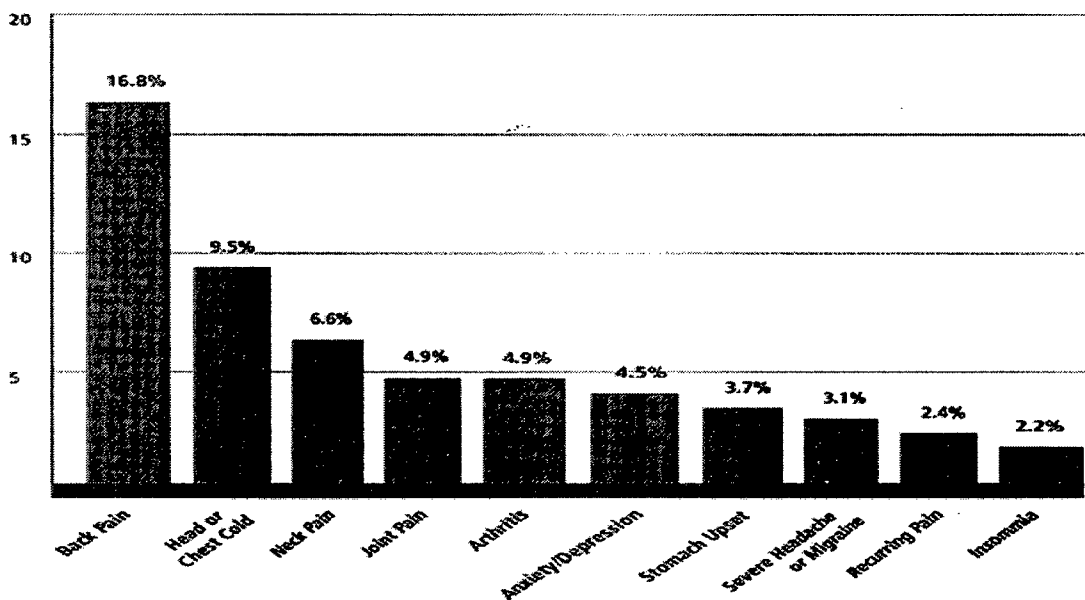
Note: The National Center for Complementary and Alternative Medicine (NCCAM) and the National Center for Health Statistics (part of the Centers for Disease Control and Prevention) released new findings on Americans' use of complementary and alternative medicine (CAM) and the findings are from the 2007 National Health Interview Survey (NHIS), an annual in-person survey of Americans regarding their health- and illness-related experiences

In the United States, close to 38 percent of adults (about 4 in 10) and approximately 12 percent of children (about 1 in 9) are using some form of CAM. People of all backgrounds use CAM. However, CAM use among adults is greater among women and those with higher levels of education and higher incomes. The primary reason which can be cited for this pattern and as one could derive from Greenhalgh's (2001) account is that CAM is used by those who are earning more (since many of the insurance companies are extremely selective about which of the CAM treatments to choose) and are basically from educated background as CAM requires a lot of research work [NCCAM (2008)] and as per Renzhofer (2010), who shares an analysis carried out by Meeker (2000), in which there were several variables that were predictive of CAM use in the previous year, including higher education levels, slightly poorer health status, a holistic orientation to

health, and a personal transformation experience, as well as specific health problems such as: chronic pain, anxiety and urinary tract and back problems. Despite an exorbitant healthcare budget and an increased use of CAM, complaints regarding chronic pain have not receded. The graphs below show an upsurge in the number of people using CAM from 2002 to 2007.¹¹

Graph 2. Disease Conditions for which CAM Is Most Frequently Used Among Adults- 2002

Diseases/Conditions for Which CAM Is Most Frequently Used Among Adults - 2002



Source: Barnes P, Powell-Griner E, McFann K, Nahin R. CDC Advance Data Report #343. Complementary and Alternative Medicine Use Among Adults: United States, 2002. May 2004.

▪ Source: Barnes P, Powell-Griner E, McFann K, Nahin R. CDC Advance Report #343. Complementary and Alternative Medicine Use Among Adults: United States, 2002. May 2004.

Menges(1994: 872), in an analysis of the state of regular and alternate medicine in Netherlands, mentions a three tier classification of patients using alternative medicine: wherein the patients belonging to the first category comprise of those who are frustrated

¹¹ http://nccam.nih.gov/news/camstats/2007/72_dpi_CHARTS/chart6.htm

from regular health care services, the second category comprises of patients who combine both regular and alternative care hoping for a total respite whereas the third and final category comprises of patients who are convinced with the efficacy of alternate medicine. Also, the author suggests that alternate medicine is used mostly in the case of chronic disorders and the attitude of general practitioners towards alternate therapies is rather positive unlike in the Anglophone world.

Greenhalgh (2001) and Jackson (2000), on the other hand, talk about inefficacy of CAM treatment in case of chronic pain, in United States. The above graphs show an increase in the usage of CAM practices, but it is clearly mentioned that even these practices are not of much help in subsiding the pain. When various healing practices are not able to provide respite to a prolonged suffering, the next major step in the unending painful journey arises. The sufferers start questioning the notions of self; their bodies defy them psychologically, emotionally as well as professionally. This makes them question the logic behind their pain, their haplessness and their bodies which appear to be as something defective and extraneous to them. A feeling of alienation towards one's own body develops.

2.5-Pain and Ethnicity

The role of ethnicity tells us many a things about pain perception. For instance, Zborowski¹² cites the case of labour pain which is accepted as a part of child birth and states that in United States various means are used to alleviate it as it is not accepted where as in Poland it is not only expected but accepted too and as a result nothing or very little is done to relieve it. Pletcher et al (2008) carried out a research to see the role of ethnicity or race viz-a-viz prescribing of opiod for pain relief.

Their research throws light on the biased approach in the clinical settings where ethnicity influences a patient's possibility of getting an opiod prescription. Morris (1991) defines ethnicity as a 'social construction, dynamic rather than static, shaped even by the methods of data collection that researchers employ to measure it'. The author states that

¹² The article titled "Cultural Responses to Pain" is retrieved from <http://www.qdocuments.com/Cultural-Responses-to-Pain--PDF.html>. No citations for this paper have been given apart from Sociology 101.

one has to be extremely cautious while choosing a term like ethnicity. However, the fact that he himself describes it as a dynamic category resolves the problem to some extent. Anne Fadiman (1998) describes the case of a Southeast Asian girl suffering from a rare, severe form of epilepsy who arrives with her family in the United States. The American doctors do not speak the Hmong language. The parents speak no English and are mistrustful of secular remedies, preferring animal sacrifice to anticonvulsants. Medical, governmental, and cross-cultural complications escalate. Although the girl does not die, she does not recover, lingering in a badly damaged state, unable to walk or talk. In conclusion, pain specialists, like other health professionals, increasingly face the perplexities—and sometimes tragedies—of ethnic difference and hence, it tends to be important for conventional medicine not only to be more open to the patient's concern but to be aware of cultural propensities which, if they may not help in curing the patient, at least, will play a significant role in making medicine a relatively better understood practice.

Honkasalo (2010) conducted a study with patients from Finnish pain centres which reflects on how people in pain end up being stiff and stubborn with medicine making their worlds all the more dark by offering no help. To reason this attitudinal shift from the past of patients which had hope to the present which looks bleak, the author ponders if it is the historical events and socio-cultural tendencies of the Finnish way of life which mould the notions not only regarding pain but otherwise too. The author concludes on the basis of her own experiences and observations since her childhood that it is close to impossible to 'ignore the Finnish penchant for melancholy, solitary drinking and suicide'. In such a situation, she states that 'chronic pain cannot only be seen as a medical phenomenon but as one of the strand in the bundle of culture postures which correlate body and self.' Free (2002: 144) cites examples from other literatures and raises pertinent questions regarding the role of a cogent understanding of cultural values and codes so as to provide efficient medical care to the sufferers. She finds the cultural gap between modern US medical system and the large number of ethnic minorities it caters to as a major problem.

“Payer and Galanti pose examples of cultural clash and resulting conundrums when they ask the following: what happens when an Iranian doctor and a Filipino nurse treat a Mexican patient?”

What takes place when a Navajo patient calls a medicine man to the hospital? What is the result when an Anglo nurse and a Japanese doctor have difficulty understanding one another? Why do Asian patients rarely ask for pain medication while patients from regions on the Mediterranean coast prefer pain medication for the slightest discomfort? Why do Middle Eastern men not easily allow male doctors to examine their wives, sisters and daughters? Most western medical personnel do not understand that coin rubbing is a form of medical treatment and not a child abuse. Between and among different fractions, the result may be confusion, conflict and misunderstanding.” [Free (2002: 144)]

Bates et al (1997: 1433-1447) list various factors like language barrier, culturally determined expressions of pain, cultural views on mind-body relationships and notions regarding pain behaviour in different medical settings which effect chronic pain and other chronic illnesses accordingly.

Despite the above arguments posited by the researchers, it is extremely difficult for the clinicians to comprehend all the differences. However, it is definitely possible that the doctors can try to know about the belief systems of patients which require them to listen to patients narratives more carefully and take note of it. Understanding that the differences exist on each other’s part can be a key to successful handling of health issues.

Similarly, Bates et al (1997) discuss the case of Polish- Americans who are inexpressive despite suffering from severe pain unlike Americans who find the slightest of pain (in relation to Polish population) as threatening. Many sociological and anthropological researches on pain show that pain is a pervasive condition of melting pot societies like US. This is questionable and the answers are hidden within the cultural notions and hence, it is crucial to pay heed to the cultural disparities regarding notions of health and illness.

2.6-Conclusion

Illich (1975) states that medical civilization changes the pain perception once it colonizes any culture. He opines that culture makes pain tolerable and it’s only the curable pain which is intolerable. Conrad (1992) states that medicalisation is a process whereby more and more of everyday life has come under medical dominion, influence and supervision.

‘medicalisation consists of a defining problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using a medical intervention to “treat” it.’ (ibid. 213)

Delmouzou (2006) believes that the availability of medical care and economic circumstances impact on health delivery system and are indicative of the degree of medicalisation, which is available within the country. He states that medicine penetrates deep into our private and public lives and extends its controls over the bodies through procedures like prescribing drugs and performing surgeries. He states that authors like Conrad (1992) have talked about the benefits of this medicalisation process. The benefits include symbolic clinical benefits like the people seeking to redefine their problem as an illness so as to reduce the possible stigma attached [as states Jackson (2000:176)]. The benefits of medicalisation often extend beyond clinic and enter the realm of symbolic. The example of alcoholism is a case in point, as labelling alcoholism as a disease protects the person from being blamed for the habit. Broom and Woodward (1996) observe in one of the studies that medicalisation is not always bad and in certain situations like in case of absence of ‘unequivocal diagnosis or lack of proven therapeutic interventions’, rather than withholding the information doctors should be more forthcoming to take the symptom of the patients very seriously. This approach renders legitimization to the doctors and they often receive support for their efforts at self-management.

“Legitimation, coherence and support are all necessary components for improved well-being.”
(*Ibid p.357*)

Unfortunately, chronic pain sufferers thrive for all the three. This perpetual and prolonged struggle makes the sufferer question one’s existence.

As per Jackson (2011), any anthropological discussion of pain sooner or later departs from the biomedical model because so many dimensions of pain lie outside, or at the extreme margins, of medicine.

“These include sex and gender (Garro 1992; Kempner 2006; Whelan 2003), social class, ethnicity (Trnka 2007), prior experiences with pain, family history, and so forth (see, for example, Good *et al.* 1992). Moreover, although biomedically and conventionally pain is seen as a property of an individual, in fact it is deeply intersubjective. The experiential world of a pain sufferer will be significantly shaped by persons participating in that world, a point made by Wittgenstein some time ago (also see Das 1997; Kleinman *et al.* 1992).” (Jackson 2011: 4)

Even while patients are made to learn the art of managing pain by accepting it as a part of life, it is easier said than done. As Jackson (2000) and Greenhalgh (2001) record in their accounts; even if the sufferer starts asserting that he/she is not feeling any pain, it remains a lived reality primarily because of its aversive nature.

Greenhalgh (2001), in her personal account, reaffirms the incapacity of biomedicine and other alternative treatments, which might sound holistic but are not in their true sense, towards the sufferings of those in pain. Conventional medicine is the dominant discourse and, in majority of the cases, plays a significant role in relieving suffering. In case of chronic pain patients one needs to look into ways using which the experiential model can be collaborated with clinical model. This requires re-humanizing the medicine, a phrase used by Cassell (2004).

Jackson (2011) places the position of patient ahead of the technological advances observed in medical science. As per her, ultimately any laboratory test result or image obtained must be interpreted and the fundamental basis of this interpretation should be the patient. She cites an instance of image obtained through MRI to substantiate her claim. According to which, MRI is only a snapshot devoid of physiology. It can account for anatomical details but not the physiological ones. However, the impact of the outcomes produced using medical technology reflects the dominance of biomedicine in people's lives.

Naraindas (2006: 2660) while addressing the central paradox of pain cites an example while explaining how biomedicine has stripped off 'Eastern' corpus of knowledge of its theory and accepted these practices by imparting them the kind of explanations biomedicine model itself relies on. Those explanations take into account the idea of a visible cause. The author refutes this amalgamation stating that such explanations are often misleading and manoeuvred. Citing the example of chronic back pain patients in US, he states that medical tests are the most important ingredients to establish legitimacy of their pain. The visual images obtained from the medical tests are not able to mark the presence of any lesions, thereby leading to the delegitimization of pain. The patients suffering is exacerbated when the individual knows that the pain has been delegitimized which further distances the patient from the clinical model.

3. Chronic Pain, Identity and Meaning: Articulating the Self

“English, which can express the thoughts of Hamlet and the Tragedy of Lear, has no words for the shiver and the headache.... The merest schoolgirl when she falls in love, has Shakespeare or Keats to speak her mind for her; but let a sufferer try to describe his pain to a doctor and the language at once runs dry.”

~ Virginia Woolf¹³

For long, the clinical side of chronic pain has been discussed where as there is an experiential aspect to the life of chronic pain sufferers' lives as well and it can be elaborated by looking at the embodiment approach which cites body as non-dualistic in nature unlike as it is perceived in the biomedical thought [Cassell (2004)]. Jackson (1994: 201) states that embodiment is one approach that can be used to examine some of the complexities of chronic pain. Csordas (1990: 8) opines that “an embodiment perspective requires that the body as a methodological figure must be nondualistic, i.e. not distinct from or in interaction with an opposed principle of mind”. In case of chronic pain, body acts as an active agent by embodying the suffering lent by pain which again has an agency to it. Pain is expressed in the form of pain behaviour. The problem lies in the fact that pain behaviour is often seen either as an attempt to communicate the experience of pain or an attempt to express affects of pain in the form of suffering, demoralization and other feelings associated with pain. Jackson (1994: 203), in her work opines that the two i.e. the pain experience and other experiences which accompany pain cannot be seen separately.

The phenomenological perspective takes into account all aspects of pain as one. Csordas (1990) refers to pain as a perceptual phenomenon of the lived world. This chapter throws light on some of the most basic and most important features of chronic pain which are responsible for its ambiguous nature. Taking a lead from the preceding chapter, where we saw that no healing practice or treatment can cure chronic pain, it becomes relevant to

¹³ Oft quoted lines from Virginia Woolf. [Cited in the endnotes in Jackson (2000: 234)]

look for reasons which make chronic pain a puzzling concept. Jackson (2000: 169) calls pain as a concept and not a thing because pain is not an object extraneous to the sufferers' body and self rather it is a concept which is applied to our experiences as well as to the inferences of what other's face.

Many developed nations are pumping money for an effective management of chronic pain and for this very reason it is utterly important to understand the meaning that the patient makes of their pain. Chronic pain patients face difficulty in coping with the changes in their body and also with their way of living. In many cases, they face a future of uncertainty and a lurking fear of increasing disability. Overtime, not being able to find an effective cure and having chronic unrelenting pain can bring a loss of self-identity and self esteem which poses threat to the career prospects of the individual suffering from chronic pain (Charmaz 1983).

This chapter delineates those characteristics of chronic pain which are responsible for its ambivalent nature and thus, make it difficult for its sufferers to articulate their problems in the presence of multiple confounding variables. This chapter also examines how chronic pain is able to break through the dualistic boundaries extant in the western world. The most important agenda of this chapter is to explore the questions about self and body after a prolonged pain which has not be effectively handled by the clinical model. A cogent analysis of experiential aspect of pain behaviour becomes crucial to see how the pain experience disrupts the lives of patients (Bury: 1982, Richardson et al: 2006). This chapter, therefore, looks into the processes and experiences involved in rendering meaning to the development of pain as well as measures taken on patients' part for remaking their identities post disruption.

The subtitle of the chapter reads as 'articulating the self'. The justification behind this lays emphasis to the constant struggle faced by the pain patients during the process of reconstruction of their lives around pain (Dickson and Kim, 2003: 685). The following discussion takes into account questions of the notion of self, identity and meaning as well as the confounding principles of body being perceived as an object or subject (Jackson, 1994: 201-227) and the role of language in grappling with chronic pain and the subsequent suffering.

A phenomenological understanding of body acknowledges the body as an active agency. It asserts the subjective aspect of body. Kugelmann (1999: 1670) cites Merleau-Ponty (1962) who refers to the body-subject as “I can” whereas for Csordas (1994) body is “the existential ground of culture.” Phenomenologists, as states Kugelmann (1999: 1670), perceive pain as a way of ‘being-in-the-world’. The pain is seen as world shattering within the phenomenological traditions [(Scarry 1985) and (Good 1994)]. The world which is talked about is life world. Pain makes as well as unmakes the world.

“From a phenomenological point of view, pain is an affliction within existence (Buytendjik, 1962). The very undergoing of pain, the handling of pain, the expressions of pain and in so doing, make the world. Not only is pain “made” as a cultural experience and set of practices, pain makes the world, the truth of utilitarian thought, for which pain and pleasure are the two springs of action. In phenomenological terms, pain is an attunement, a disposition, a way of being-in-the-world.” [Kugelmann (1999: 1670)]

3.1-Chronic Pain, Suffering and Self

Self is an inner experience of subjectivity that is both constructed through cultural processes and is inherent within the world (Honkasalo 2010). The self is embodied too which implies that at a pre-reflexive level, the body and self are one. Chronic illness disrupts this embodiment [see Toombs (127-138) in Leder 1990] and poses challenge to the sufferer.

Most of the pain literature discusses the loss of self which occurs when the patient is not able to seek relief. Not receiving a cure or a treatment which does not prove of much help make the patient bear with the pain-as-sensation aspect of pain. The physical discomfort which thus prolongs definitely contributes to the suffering. However, the suffering increases multi-fold in the dearth of evidence which can legitimate the cause of suffering. It increases when an institutional body of knowledge is not able to acknowledge and present a solution for the problem.

The expert opinion in the field of science, medicine in this case, is always acknowledged for having the power to validate or invalidate the object, in question based on observation and inferences. Validation of pain assures the patient with a cause which either has to be removed and if it is not removable, at least there is some feature which can be held

responsible for the subsequent suffering. In case of intractable chronic pain, the patient finds himself/herself all at sea, when no diagnostic measure finds the reason for the suffering. This poses a serious threat of being labelled as a malingerer which assures a stigmatised existence. The physical suffering alienates the sufferer from the body. The existing notion of self changes drastically and initial leads to a loss of self. With the passing time, the sufferer gathers oneself so as to have a peaceful survival. This action of gathering up is marked by the process where the individual learns to articulate one self. This process of articulation can be successful or unsuccessful depending on the external circumstances as well as the inner strength of the sufferer. Hence, the suffering is marked by two phases i.e. the articulation of self preceded by the loss of self.

Charmaz (1983: 170) states that the major sources which lead to a loss of self in the lives of chronically ill include 'living a restricted life, existing in social isolation, experiencing discredited definitions of self and becoming a burden'. Drawing upon a symbolic interactionist perspective, he assumes self as a fundamentally social entity implying that self develops through social relations and is maintained by the same. This concept, therefore, can be used to analyze the alterations occurring in the notion of self of a person.

Chronic pain is a grey area where the loss of self happens inconspicuously. Whatever has been previously taken for granted is all gone. This makes the sufferers highly aware of his/her own self (ibid. 170). Citing the case of American families, the author (ibid. 170-171) states that the American families are not well structured to care for ill person, especially the mother. American institutions are not able to offer alternatives and usually the drastic measure of removal of sufferer from the home is considered. This way the individual confronts and formulates his /her own concept of self as a chronically ill person. Here, I would like to add that Charmaz work is relatively old (1983) and since then the probability of possible changes in the social structure to incorporate the chronically ill cannot be ruled out. However, no evidences to substantiate it could be found out during the course of this research.

During the social interactions, the individual sufferer faces the threat of discreditation and even stigma in the face of not being able to live up to the expectations of normal world.

Chronic pain reduces the participation to a great extent and is thus, considered as a disability threat in work stations across North America (Jackson: 2000). Also, the relative importance to those who discredit the person in pain influences the individual's future concept of self direly. This pattern restricts the individual from portraying a positive image of self. 'Others may even come to believe that the ill person conspires to undermine them by performing poorly, functioning inadequately or relinquishing responsibility for self-maintenance' (Charmaz 1983: 182). The sense of being a burden on the family also leads to a discredited self. The notion of burden on others not only accounts for physical dependency but a feeling of good for nothing and uselessness as well (ibid: 190). Those who keep suffering manifest a loss of self. I came across one such comment by a chronic pain patient named Marsha while I was surfing a social networking site. It goes like this,

"My son and his wife are coming to stay with us (for) a few days and I refuse to worry about the details. My husband has promised to do some cleaning today, and I'm just going to rest so that hopefully I'll have enough energy to enjoy them at least part of their visit. Wish me luck! Marsha"¹⁴

Marsha is a chronic pain patient. In the above statement, one can clearly see the assurance rendered by the husband which makes her feel more at peace despite being aware of her incapacities. In case of chronically ill, therefore, the support of family and peers provides immense courage. This act of support and empathising can work wonders in assisting the sufferer to provide assurance helping them to retrieve the lost self.

The following discourse takes into account the features of chronic pain which problematise it. These features also throw light on the impact of suffering on self.

3.2-Pain and the Question of Identity and Meaning

Chronic pain as a research inquiry deals with multiple sociological issues especially with questions associated to identity, meaning, self and language (Werner et al: 2004). Chronic pain sufferers are constantly attempting to seek answers for questions related to

¹⁴ For more of such comments and conversations as well as to observe how sufferers unite on a virtual space to lend support to each other in the lack of any help from biomedicine, alternate health systems and non-sufferers (not always though) follow this link <https://www.facebook.com/pages/Chronic-Pain-Info/277614584113>

their identity, as their suffering and a lack of relief from it pose a challenge to their existence and to their notion of normalcy (which is different from the world they are living in). Their notion of normalcy considers pain as an intrinsic feature of their existence. The following discussion looks at certain aspects associated to pain which make it difficult for the sufferer to come to terms with the suffering in the initial stage. The discussion also tries to see how do the patients come to terms with their suffering and start to reconstruct a new self which is more suited to living peacefully in pain.

Chronic pain if looked at as an illness, can be observed as a biographical (Bury: 1982) or continual (Honkasalo: 2001) disruption in a person's life which often leads to loss of self (Charmaz: 1983). A painful body takes authority over and against its very own self. The self rots and becomes defective and disintegrated. This transforms the world they live in to such an extent that the pain becomes the central aspect of their lives. Werner et al (2004: 1036) state that it is a constant struggle on the part of the sufferers so as 'to find identity and meaning; to reconstruct their personal life histories.' It won't be wrong to say that the lives of chronic pain patients revolve around arguing for their reality in the quest of seeking approval. Richardson (2005: 31) states that sufferers of chronic illness face delegitimation of their condition and threats to their identities.

"like a story, a life also is a kind of argument: It is a way of claiming that one construction of experience should be privileged and that other, negative alternatives should be dismissed."
[Werner et al, 2004:1036]

Primarily, there are four features associated with chronic pain which problematise the notion of identity and meaning in the sufferer's life. These features include the 'polarities' (a term borrowed from Kugelmann, 1999) through which pain manifests itself. The polarities referred in here demonstrate what makes pain intolerable as well as throw light on the marginal existence of chronic pain patient.

Subjectification/ Objectification

Pain, as states Jackson (2000: 146), is a part of self because it is a bodily feeling capable enough to disrupt our lives. Simultaneously, it is not because it is due to some exogenous causes. Jackson (1994: 203- 207) discusses the lived world of pain perception and states

that in lived world neither the bodies nor the pain can be treated as objects. But, she cites cases where patients refer to pain as an object, as an 'it'. Objectification of pain is partially feasible as it is deliberate and once, the person is back from attempting the conscious segregation of body and self, they reunite again thereby initiating the pain too. While talking of pain objectifies it, experiencing it is an act of subjectifying it. Subjectification of pain makes the feeling less aversive. Hence, there are no direct conclusions about pain being either a subject or an object (Jackson 2000: 148-150). Rather it is both. Standard medical testing procedures try to objectify both the body and the pain. In our day to day lives, we act through our bodies. It is through our bodies that we experience and we acknowledge the 'self' in us. With an increase in ailment or suffering, subjectification is bound to increase as pain threatens to destroy the everyday world in which patient is living. Ironically, as Jackson (1994: 207), mentions pain is often conceptualized as a physical object present inside oneself. It becomes mandatory for those bound by the limitations of medical knowledge to see pain as an object, as something which is physical. Not doing so is liable to suspicion. But for the patients, it is more of a conundrum and they show the subjectification and objectification as per their coping styles, leading to a tussle between me and not-me, as finds out Jackson (2000: 150), during the course of her research. Hence, pain challenges the notion of body as object and self as subject. Accepting pain as a part of self makes it easier for the sufferer to get a control over one's pain.

“... And part involved integrating the pain. if you were in tune with the pain, on the side of pain rather than hating the pain, she said, you would actually feel better.” (Jackson 2000: 156)

If one looks at pain as a process of subjectifying or objectifying the experience, it can be said that this kind of behavior will definitely be individually governed based on the general outlook of the sufferer. This general outlook has not to be towards the pain experience only, but life. Kugelmann (1999: 1667) found out that patients presented multiple polarities in terms of stress and relaxation and of physical and emotional pain. On the similar lines, he also talks of positive/negative thinking polarity. Positive thinking entails strength of mind, self-assertion whereas negative thinking is a character of

weakness. The author argues that this polarity is to redefine chronic pain in spiritual terms (ibid. 1668).

Mind- Body Interaction

The second feature associated with problematisation of pain is mind-body interaction as seen by patients. In the preceding chapter, mind-body dualism extant in biomedical thought and practice was discussed. In case of some pain patients, as Jackson suggests (2000: 47), there's a tendency to talk more about the physical aspect primarily for two reasons i.e. it's a way to legitimize the self and secondly, because of the constant struggle to find appropriate language. However, in majority of the cases, some mind-body interactions were accepted as part and parcel of the pain experience.

“After first describing their pain in terms sensations produced by physical causes, most patients moved on to broader concerns such as how they felt about their transformed, pain-full selves..... Anyone with pain will be depressed, pain takes over life. you don't want to do anything because it hurts.” (Jackson, 2000: 47)

All these polarities, establish the discursive character of pain. In the light of these discursive polarities, pain tends to be a private feature of the individual which must be produced in an objective manner if it is to be portrayed as a social reality (Kugelmann 1999: 1669). Producing pain as something objectifiable becomes essential to use it as an evidence for legitimacy. Jackson (2000) and Kugelmann (1999: 1668) state that the invisible character of pain problematises it as it is difficult to be explained and understood. Its visibility via expressions and persuasive abilities of a person claiming to be in pain presents the pain experience with legitimate evidence. The pain can only be shown to others by self-display. Visible pain demonstrates the vulnerable self to others.

Hilbert (1984) states that chronic pain cannot be understood from the same lens which analyses pain per se. This is for many reasons which have been discussed till now and many more to be discussed further. The most important feature of primary pain which distinguishes it from the normal pain is it transcends physical pain. This develops a feeling of frustration and makes them feel socially isolated. Hilbert (ibid. 1984) states that they encounter difficulties in social settings and by and large, their problems related

to pain management remain unresolved. He further opines that the problems of pain sufferers are not limited to pain as a sensation, rather these problems located in language and culture.

Language and Pain

The language of pain and the language of those in pain are two aspects which are to be taken into consideration for a heightened understanding of suffering and the notion of self. The language of chronic pain is the language of suffering and with time this transforms into the language of loss of self. No doubt another self reemerges as the sufferer learns to articulate the self to fit into the everyday world around him/her. But this self is never as valued as the earlier one (Charmaz 1983: 168).

Jackson (2000: 13) cites an example of sufferers of intractable pain and discusses the constant conflict they undergo by being in pain which has no cause. This leads to alienation of the self from body. This, as per her, leads to an altered self which looks out for a language to meet the challenges of communicating not only with the alienated body but otherwise too. Scarry (1985) opines that pain shatters language completely. Language comes as the third most important aspect which problematizes the lives of chronic pain patients. Chronic pain patients require language to vocalize their suffering. Their sick role is never ending and so as to demonstrate their incapability of not being able to carry out the usual chores of everyday life, for not being able to make their bodies act as per their own whims, it tends to be important for them to be able to put their suffering into words. Jackson (1994: 212-222) discusses the language aspect in detail. Chronic pain sufferers face trouble communicating about their pain and part of the difficulty arises from the confusion regarding language being a part of mind or of body.

“...much of the language can be traced to the fact that we speak and think from an embodied perspective (see Johnson, 1987), but some aspects of this embodiment are favored over others: for example, visual perception is encoded, at least in English, far more than aural or olfactory perception (see Rorty 1979; M Jackson 1989). It is significant that we use the expression “body-language” to describe someone conveying meaning with his or her body. Body language is often thought as “primitive” or “pre-linguistic” language. [...]” (Jackson, 1994: 212-213)

Thus, Jackson calls pain as pre-linguistic. As per her, it resists language because of its invisibility, incommensurability and the reason that it cannot be ascertained by any

means but by sufferer's affirmation to its presence. Brodwin (1994: 50-77) discusses a patient's case where he comes to know that the patient uses pain as an excuse from many responsibilities, as well as to avoid certain occasions. Similarly, Richardson et al (2006:1583) quote Riessman who casts apprehension regarding the patient's version of illness or pain.

“...the ‘storyteller’ in interview creates and presents a particular self through his or her account, which an account which is constructed in interaction with the interviewer and which must also convince the listener of its veracity and its original impact on the storyteller. In these accounts, ‘the moral character of the protagonist is sustained’ (Riesmann, 1990, p. 1195).” (Richardson et al 2006:1583)

This is the central paradox of chronic pain patients' lives, pain resists to be verbal primarily because we conceive it to be of the body and hence, pre-linguistic. Richardson et al (2006: 1583) quote from Richardson (2005) that the narratives or the pain stories which appear during the course of interaction with pain patients are constructed and told to present a specific identity and use it as the means to legitimate pain. It should not be simply seen as naïve description of pain and pain experience. It is easier for the patients to talk about pain by objectifying it and the moment any explanation is thought without prior objectification of pain, the language runs dry (Good, 1994: 29- 48). Jackson (1994) shared patients claim that only fellow sufferers can understand their suffering and not others.

Jackson (2000: 143) contributes one whole chapter on self and language in her in-depth account on the experiences of chronic pain patients. She quotes one of the patients of CPC stating “The pain is me”. Jackson makes a note of transition observed by pain sufferers, their families and the staff members of CPC in the concept of self post pain experience and after the therapy. She addresses the issues of pain, selfhood and language as ‘me and not-me’. The pain sufferers are at a conflict with themselves on the issue of accepting the pain as a part of their very own self or disowning it by perceiving it as something they intend to get rid of (which rarely happens). Most importantly, the problem faced by chronic pain sufferers is how to connect the body to the self which is constantly altering. She finds out the change of notion of self amongst the pain sufferers.

When the researchers try to probe the experiential aspect of pain, patients hesitate to speak their mind to avoid the stigma of connecting pain to mental processes (ibid.).

The role of language is of key importance in the lives of pain sufferers. As per the author (ibid: 145), western culture emphasises on mind-body dualism and hence, someone 'who believes her pain is due to a physical cause (e.g. angina produced by hardened arteries) will probably experience a pain in the region of heart differently from a pain she believes to be emotional in origin (e.g. heartache caused by unrequited love). This exacerbates the suffering and alleviating it along with the pain sensation is a daunting task because, on the one hand, the language aspect for representation of the suffering is highly contested and on the other, as has been discussed earlier, it is the way westerners construct the notions regarding mind and body. As per Good (1992), such a situation is of deep concern to pain sufferers because of the stigma that comes up because of the cause which is emotionally manifested and hence, can be long lasting. Also, Jackson (1994) states that as per phenomenology, the objectification of pain happens when we talk about it; try to make sense of it.

As per Frank (1997), when one thinks of pain as outside the body, one develops a sense of alienation. Frank argues that the modernist conception of illness is a form of "colonization" in that the ill person hands over his or her body (and life narrative) to biomedical expertise. In a post-modern conception, however, the ill person reclaims the authority and ability to tell his or her own story, and to construct a new life narrative from the "narrative wreckage" of serious illness or injury. He lays emphasis on the voice of the sufferer which is so often dismissed and claims that medical culture acts to silence the ill. Kathy Charmaz (1983) claims in her work that a chronically ill state results in sheer loss of self which is one of the most basic yet severest form of suffering. Honkasalo (2010) observes that people in pain suffer from a sense of loss which subsequently results in an altered subjectivity or a changed sense of who they are. However, this transformed self will always be less valued.

“The experiences and meanings upon which these ill persons had built former positive self-images are no longer available to them. Such losses are most marked at the onset of a serious, debilitating illness or at points when ill person define former actions, lives and selves as now precluded by illness. Overtime, accumulated loss of formerly sustaining self-images without new ones results in a diminished self-concept.” (Charmaz 1983: 168)

Leder (1990: 69-99) in his work discusses body experiences which involve dysfunctionality. He states that 'body seizes our awareness at times of disturbance, it can come to appear the "Other" and opposed to the self' (ibid. 70). This way pain reorganizes the sufferer's lived space, time and the relationship with others as well as the self.

Jackson (2000) in her account on the chronic pain patients discusses the significance of pain behaviour. She (1994: 203) states that from a phenomenological perspective it gets difficult to make a clear distinction between 'pain behaviour, experience of pain and the emotional states accompanying pain'. Given this, she concludes, an intractable chronic pain is an extremely distressful condition leading to a great deal of suffering. Kleinman (1988) states that pain shatters the inner as well as outer worlds of sufferers and the moment any pain or illness is labelled as 'chronic' it tends to be a baggage with many unspoken implications.

"After describing their pains in terms of sensations produced by physical causes, most patients moved on to broader concerns such as how they felt about their transformed, pain-full selves." Further, she quotes a patient who suffered migraines stating that "anyone with pain will be depressed; pain takes over your life. You don't want to do anything because it hurts."... Jackson (2000: 47)

Pain and the Role of Culture

Culture is the fourth most important aspect, understanding which is not only important to have an empathetic understanding of the lives and suffering of pain patients' but because of the reason that it can play a significant role in effective health care management.

Charmaz (1983: 169) is of the opinion that this loss of self develops out of daily life. Citing the American way of life as one crucial reason for this extended suffering, the author combines aspects of everyday life like 'payment plans, patient-doctor relationship, cultural beliefs and medical ideologies' as factors spiralling the suffering. The problem does not lie in pain. As Jackson (2011) states, pain as a biological category is an indispensable part of life. It is the factor of chronicity which tends to make it difficult for patients, practitioners as well as those around the patient. The suffering takes a toll on the social relationships. It significantly alters the notions of one's own identity.

The puzzling notions regarding chronic pain stem from pain being an experience as well as a sensation. Its invisible character, its subjectivity and the challenge it poses to Cartesian mind-body dualism are responsible for it being capable of altering self. As per Jackson (1994: 211), it becomes imperative to look at pain as an object permeated with culture and meaning instead of taking it on its physical face value i.e., as a sensation.

Bates et al (1997) cite an example of a young man from Puerto Rico who shifted to US. Despite shifting to US, his notions could not change much. Being a patient of chronic pain he felt disabled which affected his self-image. Puerto Rican notions have certain gendered role expectations and man's ability to be self-sufficient and his role as a giver to family symbolize his manhood and self-esteem. Loss of work and related compensations due to chronic pain exacerbated his suffering and made him conscious about his own self. Werner et al (2004: 1042) state that pain patient narratives always project a conscious effort on the part of the patients to maintain a positive self-image.

Jackson (2011) demystifies the distinction between physical and emotional pain. She states that pain is monistic in nature and cannot be split up into organic or psychological components. Quoting an eminent neurologist, Howard Fields, she states that mental or emotional pain is ontologically identical to physical or bodily pain. As per her, once this point is understood, all the confusion regarding pain are busted and psychologically induced headaches and analgesia in trance appear less arcane and less astonishing. She states that experience of pain is always both 'mind' and 'body', simply because pain is always embodied! Actually, the distinction between physical and emotional pain refers to the cause and not the pain itself. The moment we refer to the pain as physical pain, we are hinting towards its cause and not the actual pain. Jackson (1994) states that the conventional model of pain focuses on the nonceptive causes and forgets that pain always has multiple causes.

When pain remains as it is despite the treatment, the sufferers begin to rely on their relationships with outside world so as to make others (as well as themselves) understand their experiences and sound meaningful at the same time. Outsiders, i.e. the non-sufferers, are not going to make much sense of it primarily because of not being able to experience. However, it can be done more easily within the groups of sufferers. Social

interaction, thus, is the key to comprehend and thus make meaning of their suffering. This kind of interaction is limited to people working in similar environments or even at places where they can find others with similar kind of suffering (Jackson: 2000; Good et al: 1994). Hilbert (1984: 365) cites Kotarba's (1983) work in his research and states that interactions among blue collar workers and athletes have been recorded which show a similar pattern. Kotarba (ibid: 365) refers to it as chronic pain sub-culture wherein new subcultures enable the sufferers to share their experiences in a way that their suffering seems as typical and understandable despite its aversive nature. But for those sufferers who are devoid of any subculture, it is difficult to understand the meaning of their suffering. For them, to understand pain in its social sense is difficult.

This makes us question if 'subculture' is the magic potion much needed by the pain patients is it going to bring end to the suffering in patient's lives? But one cannot ignore the patient's attempts to seek a proper diagnosis despite finding empathizers' around. Diagnosis has a special role in patients' lives. It's a threefold (Hilbert 1984: 368) assurance that renders legitimacy to patients suffering. Firstly, it renders hope for a treatment or cure that will end pain. Secondly, it is the advantage of being bracketed under the disease-category which makes it easier to describe one-self to others around. Lastly, as the author, mentions, a diagnosis reflects an orderly world. It assures the sufferer that there are others like him/her, that his/her condition is not unheard of and incomprehensible, that he/she sounds sane to others.

"Burgeoning pain clinics across the United States give the impression that chronic pain is an identifiable condition, that it can be treated; this impression is itself a partial remedy to the problem of meaning of pain. Patients find comfort in discovering others with the 'same' condition." (ibid. 369)

A Case Study of Older Korean American Women: Articulating their lives and their identities by reconstructing the meaning of pain

In a cross-cultural setting, the problem of reconstruction of identity is all the more grave. Studying the pain experience of older Korean American women suffering from osteoarthritis, Kim and Dickson (2003: 675-686) found out that these women had consistent pain and they reconstructed their life through a five stage process. The first

step begins with the suffering and the subsequent struggle to get rid of pain by relying on western medicine. This struggle is initiated by concerns regarding pain and the resulting discomfort.

The research conducted by authors suggests that after spending substantial amount of time, money and energy the patients express disappointment in western medicine developing a loss of self-esteem and begin to acknowledge pain as a sign of aging. This can be looked at as the first step towards legitimating one's pain. As the process continues, the medicines do not work and they try to shift from American physicians to Korean American physicians so as to make themselves more comprehensible to the doctors but to no avail and the patients stumble along with the pain making unsuccessful attempt to get rid of their pain which seems like a disease symptom by now. The next step includes reliance on self care and use of ethnic treatments but sooner it is realised that even traditional medical system has little to offer. And when both western and traditional pain relief methods prove inefficacious the patients are left with no choice but to integrate their own reason to make their pain manageable and tolerable to them. In this very case, the women patients try to pursue the Korean way of life by seeking culturally sensitive methods of pain management. Also, they attempt to make their pain 'manageable and tolerable through a process of changing the meaning of pain from pain as a medical system to pain as a sign of growing old' (ibid. 686).

The above discussed case study not only throws light on the persistent role of culture but also provides a cogent picture of how individuals in pain find relief by articulating their pain experience and thereby giving a meaning to their suffering.

On the contrary, Hilbert (1984) speaks of the acultural dimensions of chronic pain. He states that the cultural resources which usually provide meaning to pain often prove inadequate when pain persists. He is of the opinion that the pain folklores are effective in case of normal pain. In case of chronic pain, those explanations do not fit in. Despite the fact, that chronic pain needs a completely different explanation when compared to normal pain. It cannot be denied that chronic pain patients are also a part of subculture constituted of sufferers (ibid. 1524) bearing similar dilemmas.

Other than the four features discussed above, there is a performative aspect which assists the sufferer in articulation of the self. While looking at pain as a performance, one inadvertently ventures into the bodily territory. Pain performance is not only important for displaying the distraught self to others; rather, it is a way through which patients ascribe meaning to their wayward bodies. In case of any chronic illness, and not chronic pain only, bodies go out of control and rule the self. It becomes imperative for the patient not to lose control over the body as this can bring shame and in many cases stigma as well. The problem of incontinence amongst grown-ups is a case in point.¹⁵

3.3-Pain and Performance: Presentation of self and attributing meaning to body

Brodwin (1994) states that chronic pain is an effective idiom of communication in its own right. In the very article, he renders a dramaturgical explanation to pain and claims that the language of chronic pain has a crucial role to play in the changing social relationships of the sufferer. He elucidates the performative aspect of pain. The term 'trajectories', as has been used in the title of the work, represents the social unfolding of an illness. Brodwin (1994: 91) explicates the dialectics of pain and performance by beginning with the distinction between course and trajectory of an illness. The course of sickness is defined as its physiological unfolding while the trajectory of an illness is the social unfolding of an illness. This trajectory tends to be inherently problematic unlike in the case of acute pain. Acute pain, as elucidates Brodwin (1994: 90), is distinct from chronic pain on two grounds. First being the time frame and second being the interaction between family members, peers, health practitioners and the sufferer. In case of acute pain, as he states, the performer is none other than pain itself. The sufferer and others are the audience who witness the plot and wait for it to finish. In case of chronic pain, the performance differs because of the chronic factor. There are cycles of performances and the usual conventions involved in during the enactment of acute pain are not applicable in case of chronic pain. In case of chronic pain patients, this performance is never ending rather it becomes the most salient feature of the life of sufferer.

¹⁵ For more on this read S. Kay Toombs article, based on personal suffering, titled "The Body in Multiple Sclerosis: A Patient's Perspective" in Drew Leder's. 1992. eds. *The Body in Medical Thought and Practice*. Dordrecht. Kluwer Academic Publishers: 127-138.

The performance aspect of pain leads to a dramatised self. The private sensation should come out of the closet for a public display so as to communicate the problem. The constant need of performing pain is definitely going to add more complexities to the lives of sufferers (ibid. 92-93). On the contrary, this provides sufferers to enact their performance or their pain accordingly.

Therefore, the self thus determined is conscious of efforts being put to construct an identity which is socially viable. Thus, the pain symptoms which are unaccounted for by any known pathology have to discover another outlet to portray their visibility. Pain performance is the first step in this direction and the painful body is the tool which enacts the pain for others to see. The communication of pain through language is severely marred by the sensation. In the preceding discussion, body has been portrayed both as a subject as well as an object. However, it becomes important here to understand that body actively engages in constituting pain. It embodies the discomfort and suffering of the sufferer. A visible wince in pain is any day more communicative than suffering quietly.

3.4-Conclusion

Hilbert (1984: 367) states that chronicity should not be seen as an element of chronic pain simply linked to what otherwise would have been pain (acute pain). It fundamentally alters the whole experience especially the sufferer's conception of affliction. Moreover, chronic pain can never be recognised in its initial stages. It changes its course from only being a physical anomaly to disrupting the social image thereby leading to an altered self. Its reality dawns upon the sufferer gradually, thereby, exacerbating the suffering. Hence, the meaning associated with pain is a mix of biological, social and emotional influences.

Kleinman (1988) states that when pain is perceived as a threat to one's physical existence or causing harm to one's identity, then a negative meaning linked to pain amplifies the physical sensations experienced by the patient. The reason behind the amplification of suffering is not to be decoded in physical terms only. But the sufferer perceives it to be physical degeneration. The aspects like loss of self, social isolation and sense of being a burden on near ones are realized as result of suffering and not as the source of suffering by the sufferer. The narratives of suffering are often shaped in a way

which gels well with the normative biomedical discourse, which is the dominant voice, (Werner et al: 2004) and hence, provides the possibility for legitimizing the sufferers' voices and credibility to their expression of pain which is so often conceived as dubious, unreal and a figment of imagination. This once again establishes the dominance of biomedical discourse when it comes to pain treatment or management.

While explicating the usefulness of storytelling, Werner et al (2004) perceive the notions of altered sense of self as a coping mechanism for the sufferers in the absence of permanent relief. This articulation is extremely important to boost one-self for being able to face the challenges everyday life presents. These challenges are about being able to sustain relationships, assert one's identity, demonstrate normalcy despite being under constant pain and above all, putting up a brave face every day despite being aware of personal incapacities.

Literature on pain research advocates a Bio-psychosocial approach for a better understanding of chronic pain. Bio-psychosocial model (Bendelow and Williams: 1996) holds patient's self report and their subjective nature as extremely important components for developing an understanding into the multi-factorial nature of chronic pain in comparison to the prevalent focus on the 'objective' biomedical factors which are considered relevant to the management of pain in normal course. Many of the pain researchers (Baszanger: 1989; Bendelow and Williams: 1996; Bury: 1982 and Charmaz: 1983 and Jackson: 2011) suggest that for a successful implementation of Bio-psychosocial approach it is essential to overcome the traditional divides between positivistic approaches to clinical examination and incorporating an inductive understanding of subjective values and meanings rendered by patients to their illnesses.

Despite these propositions, the world of chronic pain patients is yet to witness a holistic knowledge system which can keep a check on the suffering. Cassell (2004: xiv) talks about bringing changes in the curriculum of medical schools which implies tempering with the basic premises on which medical thought and practices are based. However, he cites difficulties in meeting this challenge by stating that, "With few exceptions, the worldview knowledge and disciplines trying to gain entrance to medicine and parity in the curriculum are based on subjective. No matter how attractive many of these newer

concepts are, some seem incurably vague, the goals of others are difficult to divine and research on others is obscured by the attempt to make them scientific.” The author proposes newer explorations and newer ways to devise methods of testing. Till such methods are discovered, chronic pain and other chronic illnesses will be a conundrum for patients as well as practitioners with the former struggling for a meaningful existence till the pain lasts.

4. Chronic Pain and Ignominy: Negotiating Stigma

The normal and stigmatised are not persons but rather perspectives.

~Erving Goffman (1963, 138) [Kleinman (1988: 158)]

In the preceding chapter we had a look at the processes which lead to the loss of self as well as the manner in which the sufferer comes to terms with the pain. However, coming to terms with the pain does not guarantee relief from suffering. It definitely sublimates the excruciating experience. Also, experiencing the pain on daily bases, every now and then, makes the experience routine, eventually, not leaving the sufferer flummoxed at the appearance of pain.

“Managing chronic pain is uniquely problematic. Cultural folklore governing the expression of pain, however varied (Zborowski, 1969), pertains to normal pain. When pain is chronic, one might expect the appropriate method of managing it to become chronic also. But when these methods become chronic, they cease to be appropriate. One cannot moan all the time; one cannot confide or expect deferential treatment all the time; one cannot quietly withdraw for the rest of one’s life; one cannot even conceal such an object of one’s attention all the time. Thus, culture fails once again to tell sufferers how to handle pain.” (Hilbert 1984: 370)

The sufferer lives in a constant dilemma without being aware when his/her woes are going to end. Kleinman (1988: 181) writes that “chronicity for many is the dangerous crossing of the borders, the interminable waiting to exit and re-enter everyday life, the perpetual uncertainty of whether one can return at all.” Despite the relative mitigation of pain reactions with time, which used to be of startling nature in the initial phase of chronic pain syndrome, the suffering lingers. Not in one but multiple forms. The articulation of the self only prepares the sufferer to face the challenges of everyday world. This altered self is less valued (Charmaz: 1983) and suffers from severe complex of not being healthy and capable enough to be a part of normal every day world. There is a conscious effort not to display the incapacity and the subsequent suffering. It requires the sufferer to put a brave face and resist complaining or ranting. But it is a constant fight, which is to be fought every day. And since it comes as a compulsion and an obligation without which a peaceful sustenance is not possible, it

burdens the self. This shows in everyday routines and exposes the never ending suffering to the world of non-sufferers. Parson (1951) states that sick role have a time factor associated to it. After a while, sick role comes to an end and the individual returns to routine life.

In case of chronic pain patients, as has been discussed in the last few chapters as well, the pain does not end. Its pervasive infiltration into the life world and its constant presence make it an intrinsic feature of the patient's life. So much so that the relationships, professional life as well as the inside world of the sufferer are greatly influenced as well as regulated by the pain. Being in constant pain mars the work efficiency of the sufferer. Constant pain hampers the day to day activities. This brings shame to the person who is trying to match up to his/her previous self. The shame of not being able to carry out all those activities which were ones considered trivial, the shame of bringing in pain as a ruse every time one is required to participate in the everyday world affairs, the shame of complaining about pain all the time etc. make the patient fear getting stigmatised as a malingerer, as crazy and lazy and as someone who feigns illness. This results in self-blame and self doubt. The fact that pain can be everlasting is incomprehensible to the non-sufferers. This very notion casts suspicion on the suffering and pain experience of the sufferers and aggravates their shame, simultaneously invoking stigmatic reactions from those who are not in pain.

The present chapter looks into discourses associated with stigma and tries to raise an argument seeking measures for the avoidance of resultant suffering of chronic pain patients. The trajectory of pain is not cyclical but linear with too many overlapping and back and forth movements. The epigraph at the beginning of introduction, i.e. the first chapter, substantiates the above statement. Pain, thus, appears to be an existential situation and makes one question the notions of normalcy existent in the world whereby any abnormal condition, in this case being in constant pain, visible or invisible, is vulnerable to stigma. This chapter, further explores, the issue of negotiating stigma. In the previous chapter, 'articulation' was used as a trope while in this chapter 'negotiation' will be employed as one. Articulation of self is the first step to a meaningful survival especially after all the meaning (sense rendered to various acts and

artefacts of everyday life) is depleted post-pain experience. In the dearth of effective medical interventions, the onus of providing a meaning to the illness/pain solely lies with the sufferer. This comes as the initial step towards managing pain. The meaning can be rendered by altering the self in accordance with the pain. Pain, thus, has an agency. Self can be altered by indulging in a dialogue with self and body (keeping in mind the basic premise of Cartesian dualism). The process of articulation begins when the 'suffering self' makes itself understand and adapt to the drastic changes that have occurred in the everyday life world of the sufferer. Articulation signifies bringing the fallen pieces together. It's a process of imparting meaning.

On the other hand, negotiation as a trope safeguards the imparted meaning. It's a process wherein, the sufferer is responsible to make peace between self, body and societal notions as well as societal perceptions. Negotiation is an obvious second step, post-articulation, to safeguard the articulated self. The process of negotiation intervenes with both internal and extraneous elements responsible for casting apprehensions as well as undermining the altered self. These apprehensions and the undermined self can possibly give rise to shame. In addition, the ambivalent nature of chronic pain invokes stigma (Jackson 2005: 332). Hence, negotiation of self with stigma, which acts as an oppressive entity, emerges as an imperative measure to manage pain in the lack of cure or treatment options. Nowhere does it imply that articulation becomes the first step, ahead of negotiation, in the trajectory of chronic pain. Negotiation assists in articulation and vice-versa. Both the processes are mutually inclusive. And, thus, cross as well as overlap each other's path at many occasions during the course of chronic pain.

The issue of stigma in case of chronic pain patients has not been explored to a large extent yet [Jackson (2005) and Honkasalo (2010) are amongst those handful of social scientists who have developed an argument on stigma and chronic pain using the concept of liminality proposed by Turner (1969)].

4.1-Stigma and Shame of being in Pain: Exploring Reasons and Repercussions

Stigma is a term which is frequently found in literature associated with chronic conditions (Joachim and Acorn, 2000). Goffman (1963) states that stigma comes from Greeks, who were extremely visually perceptive, and refers to bodily signs describing something unusual and bad especially in terms of the moral character. Goffman (1963) describes three types of stigma namely, of physical deformities, of character blemishes which incorporate traits like dishonesty, weak will, addiction or mental illness and the third one is tribal stigma which is because of race or religion. He claims that individuals associated with stigmatized conditions pass from a 'normal' to a 'discredited' or 'discreditable' social status by which he means if the source of stigma comes in full public eye and is hence visible, the stigma is highly discrediting; on the contrary if it is concealed from others 'it renders the affected person discreditable' (Kleinman, 1988) . In his seminal work on stigma, Goffman (ibid) incorporates psychological as well as social elements.

However, Kleinman and Clifford (2009) discuss stigma as a socio-cultural and moral process. As per them, Goffman (ibid) expounds stigma as a process which is based on the social construction of identity. They state that his ideas have been mainly employed for the analysis of psychological impact of stigma on individuals primarily focussing on processes by which stigma moulds the individual behaviour and is internalized, excluding the social aspects of stigma as to what are its consequences on social life. They cite Link and Phelan (2001) whose model of stigma talks about 'structural discrimination or the institutionalized disadvantages placed on the stigmatised groups' and state that this further brings to the fore the ways in which power shapes the distribution of stigma within a social milieu.

The notion of stigma as studied by anthropologists is about the stigma embedded in moral experiences. Yang et al (2007) elaborate more on this. They propose stigma as an essentially moral issue which is often ignored by other social scientists. They opine that the local social worlds are of utmost importance in case of stigmatised people so as

to understand about the stigmatizers and to see what is at stake for the sufferers? They cite Link et al (2004) stating that stigma appears to be a shared existential experience and thus, a universal phenomenon if observed from a cross-cultural perspective. However, it has to be noted that all kind of discrimination cannot be clubbed under the umbrella term stigma.

“Historically, Foucault (1977) and others (Farmer, 1992; Gussow, 1989; Shell, 2005) have demonstrated that stigma varies in degree and quality in distinctive epochs owing to different administrative and legal discourses. Across cultures, the meanings, practices, and outcomes of stigma differ, even where we find stigmatization to be a powerful and often preferred response to illness, disability and difference”. (Yang et al. 2007: 528)

In conclusion, if one looks at stigma as embedded in moral experiences, it is easier to observe the local world of stigmatised where stigma has the ability to threaten the ordinary belongings like relationships, life chances etc. of the stigmatised. Hence, even if stigma might share its features univerWellard it is not being forgotten that its impact is most strongly felt in the local world. Joachim and Acorn (2000) have talked about stigma in case of visible and invisible chronic conditions. They state that if the signs of stigma are visible to others the person is often ‘discredited’. However, in case of invisible signs of stigma the individual is ‘discreditable’ but not discredited till the time others come to know of the very condition.

There have been gaps in the existing literature on stigma. Goffman (1963) states that an individual is stigmatised by the society often when its source of stigma is visible to others, on the contrary, Conrad (1992) (1993) opines that state of stigmatization is more dependent on how the individual chooses to see himself rather than based on society. Also the social stigma is a de-legitimising social process derived from both popular and medical views of chronic illnesses. The stigma of illness affects an individual in three ways; firstly, it alters the concept of self in the sufferer, secondly it affects the capacity to adapt to the illness and finally it has a strong impact on suffers social networks. Stigma is an important variable to understand and explicate the social processes responsible for transforming self, a concept which has been elucidated in detail by G H Mead (1967). Self has been widely discussed in sociological discourse as a social construct (Berger and

Luckmann, 1967). Arthur Kleinman (1988) in 'The Illness Narratives' states that the concept of stigma is extremely useful while one adjusts to illness and it provides an insight into various phases of illness passage.

One can observe ample literature on studies related to stigma and chronic illness. However, when it comes to chronic pain one finds a limited set of work. Across the internet one can find bloggers narrating their chronic pain experiences and sharing with others the stigma they have suffered with. A famous social networking site has almost 40,000 people from across the world who are members of communities titled 'But you don't look sick.com', 'Not all disabilities are visible' and 'Chronic pain Info'.¹⁶ Here people come to share a reality which is difficult to understand or even fathom by those who are non-sufferers. The personal accounts on the shame of not being able to do simple tasks of everyday life and constant negotiation which the sufferers undergo to cope up with ignominy and stigma of chronic pain have flooded the virtual world which acts as a platform for sharing, making bonds and above all garnering assurance for their lived reality (Refer to Appendix I).

Here one observes the frustration the stigmatized sufferers have undergone. It is not only the worthiness of sufferers' self that is at stake rather even steps like seeking medication that are susceptible to label the patient. Chronic pain patients require opioids (Jackson 2011) for getting rid of pain. the regulations regarding the prescription of opioids are extremely stringent depriving most patients of their right to stay pain free. Most of the doctors fear being implicated in case the patients misuse these prescription drugs. Opioid dependency poses a threat to health care professionals being charged for reluctantly prescribing drugs. National Centre for Ethics in Health Care report (April, 2005)¹⁷ cites following statement,

"Yet despite significant improvements in pain management in recent years, patients still encounter barriers to receiving effective treatment, especially patients with chronic pain. The most important is what some have called "opiophobia," health care professionals' reluctance to prescribe opioids for fear patients will become addicted and/or divert or misuse the medications." (p.1)

¹⁶ <https://www.facebook.com/pages/Chronic-Pain-Info/277614584113?ref=ts>

¹⁷ http://www.ethics.va.gov/docs/infocus/InFocus_20050401_Opioid_Therapy_for_Chronic_Pain.pdf

The report provides various points on how to assist chronic pain patients. One of the significant steps is to acknowledge addiction and its cause in a positive manner rather than stigmatize the individual.

“Pseudo addiction is an iatrogenic condition that results when under treatment of pain leads patients to behave in ways that seem to suggest addiction—e.g., apparent “drug-seeking” behavior, such as requests for increasing doses of medication. Underlying illness and treatment itself can also lead to states, such as impaired cognition, that may be mistaken as indicators of substance abuse. Great care must be taken not to stigmatize patients as “addicts” or “abusers” when in fact their aberrant behavior stems from such causes.”
(p. 1)

The stigma of being an addict or a drug abuser aggravates the suffering. Also, the patients are left to bear pain in the wake of stringent laws, thus, not providing an effective treatment. In case of pain medication, on occasions patients are prone to drug toxicity in numerous ways. Greenhalgh (2001: 283-285) elaborates her deteriorated eye-sight post usage and an improvement in the sight after she stopped taking a particular medicine. She adds that no medical faculty could establish the side effects of drug but she had already faced it.

Another possible reason for stigmatization of pain patients can be attributed to the nature of symptoms. Pain in its milder forms occurs across the population and because of the incommensurable nature of pain it tends to get a little difficult for the non-sufferers to take pain, without any bodily lesions, as a serious case of discomfort. Richardson (2005: 45) cites Bury (1991) who suggests the problem faced in seeking legitimization for conditions where symptoms occur in milder forms in the normal population. As per him, the everyday nature of the symptoms may exacerbate the disconfirming responses when the sufferers attempt to communicate the nature of their discomfort. These symptoms are considered as trivial. Therefore, the threat of stigma and quest for legitimacy increase in contested conditions which almost exclusively rely on patient's experience for communication. More so, when the symptoms are largely invisible, everyday and trivial the struggle increases and negotiation at the level of self grows tough with time.

4.2-Pain Patients as Liminal Entities and Stigma: Non-Sufferers engaging with the sufferers

Anthropological approaches to stigma look at the processes through which stigma gets embedded in the moral life of the sufferers (Yang et al. 2007: 1528). The authors (ibid. 1528) cite Kleinman (1997, 1999, and 2006) according to whom the moral experience refers to that part of everyday life and practical engagement which defines what matters the most in common man's life. Stigma as a fundamentally moral issue implies that the stigmatized condition threatens all that matters to the sufferer. Stigma is not only a response to sociological determinants rather it is a tactic to keep the perceived threats at bay. Young et al (2007) state that the non-sufferers or the stigmatizers employ stigma as a self-preservation tool. The stigmatized, on the other hand, bear the brunt.

Honkasalo (2010) says that a long term illness becomes an identity. In case of pain patients too, pain becomes their identity. Chronic pain patients, as per the author, represent their pain as merging with body-self and sometimes distinct from the body. This kind of explanation has also been given by Jackson (1994: 204). There is a difference in the way the two approach the subject/object distinction. Jackson (ibid.) looks at it as a dialectic relationship while Honkasalo (2010) perceives both as interwoven within the body-self. Since biomedical diagnostics are not able to demonstrate a visible location of pain in case of chronic pain syndrome, the patient is declared as healthy, therefore, chronic pain remains as an in-between category and patients regard themselves as liminal i.e. being neither healthy nor legitimately ill. As a consequence, chronic pain patients are easily stigmatized.

Chronic pain patients and the health care deliverers are known to have the worst relations in biomedicine (Jackson 2005:338). This is because of the reason that the pain patients fall out of the category of patients which physicians are eager to treat. Jackson (ibid. 338 cites Gamsa 1994: 23 and Gordon: 1983) states that pain patients rather fall into a category of being 'a pain' themselves-a "crock".

The stigmatisation of pain sufferers begins at the doors of the hospitals. This implies the care givers act as active agents in the process of stigmatization. The relationship between pain patients and care providers is often a seriously deteriorated (Greenhalgh 2001) one and this invokes hostility in caregivers. The reasons cited for the frustration among the caregivers are [as discussed by Jackson (2005)] practitioner's failure, noncompliant patients; patients who "shop" for doctors with liberal pain medication prescription policies; patients who obtain pain medications from more than one physician; and patients who clearly need to be weaned from the health care delivery system. This frustration results in health practitioners stigmatizing the patients. However, it should be noted that stigmatic reactions are implicit and not direct in most of the cases. Ironically, in the lives of chronic pain patients, the factors which any non-sufferer would have considered a boon transform into bane. The invisible character of pain makes it a nebulous category, the factor of chronicity makes it questionable and the resultant pain behavior evokes stigma. Most of the patients, in their narratives (Jackson 2000; 2005) express a desire for having a visible condition, preferably some cancer, because it is a known diagnosis with treatment possibilities. The lack of visible conditions, as considered by some pain sufferers (ibid.) creates conditions for stigmatization.

Often, sufferers are seen to gain from pain and therefore are considered as partly responsible for their condition (ibid. 340).

"Three kinds of gain are distinguished in the clinical literature. Primary gain diverts the patient's attention from a more disturbing problem (Hahn: 1995: 26). Secondary gain, as noted above, is the interpersonal or environmental advantage supplied by a symptom (s). tertiary gains involve someone other than the patient seeking or achieving gains from the patient's illness (Bokan et al. 1981: 331)." (ibid. 340)

The author (ibid.) states that in case of primary gains. The sufferer is not held responsible for the condition. The personhood of the sufferer is diminished. In case of secondary gains, the pain lasts till the time advantage has not been obtained. However, as mentions the author (ibid. 341), both the diminished personhood in case of primary gains and the responsibility associated with secondary gains are

stigmatizing. Also, the discrepancy between pain experiences and pain communicated is a major source of stigma. Pain behavior is an attempt to communicate about experience of pain or about the feelings which are associated with this experience. Separating pain experience from the associated sufferings is close to impossible for the sufferers and that is why they try to conceal their pain as it can invite doubt. Thus, pain is doubly paradoxical: it is quintessentially private experience that depends on social action to make it real to others, yet the very same actions can also arouse suspicions about its reality (ibid. 342).

Chronic Pain and Liminality

Turner's (1967, 1969) concept of 'liminality', as discussed in the first chapter, is used in medical context as one of the major categories of the experience of illness. He defines liminality as a stage of transition, as a space between and betwixt the normal, day to day cultural and social life – a particular space, which serves to reverse individual roles or social status. Jackson (2005) refers to chronic pain patients as liminal beings. She states that despite pain being an invisible entity, unlike visible marks, it often stigmatized (according to the patients). To understand how, it is important to know how liminality is explained. As per Turner (1967, 1969) liminal phenomenon do not conform to the logic of people's understanding of the way their world is constructed, challenging and threatening the 'naturalness' of culturally constructed categories., the phenomenon may be stigmatizes and considered as defiling and polluted. Liminal phenomenon is often tabooed and is bracketed in special categories, especially in case of rituals. The basic explanations of this bracketing process are – a functionalist, social-structural explanation and a psychological-functionalist explanation. The former explanation argues that liminality reveals fissures and dilemmas in rules and classifications and emphasizing it in symbol and rituals is basically a way to appropriate the ambiguity which be threatening. The importance of ritual is, thus, to illustrate the importance of order and unambiguity. Jackson (2005: 343) cites Max Gluckman (1963) who argues that 'ritual and formal behavior, in general serve to keep potentially confused, ambiguous and conflictive social roles distinct by highlighting their

difference'. The psychological-functional explanation argues that "betwixt –and-between" phenomenon disturb one's sense of order and purpose and that assigning them to their own, special categories relieves anxiety and reestablishes a sense of order and control.

With this as the theoretical background, it becomes easy to understand chronic pain's liminal character and the resultant stigmatization. Jackson (ibid: 343) cites Kiramayer (1988: 83) who states that,

"mind-body dualism is so basic to western culture that holistic or psychosomatic medical approaches are assimilated to it rather than resulting in any form of practice. Distress is dichotomized into physical and mental, real and imaginary, accident and moral choice. The duality of mind and body expresses a tension between the unlimited world thought and finitude of bodily life. It provides a metaphoric basis of thinking about social responsibility and individual will."

As we have observed earlier too, chronic pain moves around in the classificatory space and does not stay located at one place. It straddles mind-body boundary. All these characteristics make pain liminal in nature. Liminal categories have unstable ontological status which leads to their stigmatization.

Jackson (2005) cites Edward E. Jones et al (1984) as per whom the process of stigmatization contains four phases beginning from stigmatizers, who are referred to as markers by Goffman (1963), grouping the people together who share similar features demonstrating stigmatization or the mark. Jackson (2005, 339) refers to it as 'categorical interference' and states that in most of the cases the stigmatizers incorporate many attributes of their personal choice to this group. This hampers the whole identity of individuals leading to a loss of identity in a way that only the negative traits attributed by the markers tend to be salient. However, as she observes, the stigmatizers often realize in the obvious lack of evidence that their negative reactions are baseless which in turn generates feeling of sympathy and guilt. This generates a feeling of ambivalence further negotiation leading to conflicting selves.

Jackson (2005) further enlists work from social and behavioral sciences where stigma is analyzed from four perspectives. The first is concerned with coping up with stigma especially during face to face interactions. The second perspective is social labeling which makes the sufferer perceive one to be a part of the label provided by the markers. The third perspective, supporting which the author cites many studies, is a process related to self labeling called as secondary deviance wherein the individual starts behaving in a deviant manner. The final and fourth perspective observes the hostile reactions towards those who are stigmatized as obvious consequences of being perceived as a challenge to the prevailing social order.

Bates et al (1997: 1443), while discussing the effects of cultural context on chronic pain and illness throw light on cultural values which shape the understanding of health care providers and their attitude towards chronic pain patients. The authors compare and contrast the American notions of individualism and self-responsibility with those of Puerto Rican cultural values rendering and receiving support from family and outside as well as a strong idea of family interdependence and reciprocity. The two cultural notions are polar opposites of each other and this becomes clear in the medical settings. For instance the Puerto Rican medical centers do not hold the patients to be responsible for their suffering and thereby, help them by preventing self-blame. On the contrary, in American pain centers one observes a sea change in the way patients suffering is dealt with, due to which, patients start blaming themselves, which gives rise to shame, helplessness.

Also, the role of state policies as far as health regulations and reforms are concerned often leads to stigmatization. Chronic pain patients are usually the 'other' for many reasons. For instance, their status vis-a-vis powerful painkilling medication (opiod dependency as discussed earlier) and the availability of disability funds label them as drug abusers/ addicts and freeloaders respectively (Jackson 2005: 344). The author (ibid) calls these sufferers as 'out of place' as collectively they shift back and forth between regions inhabited by 'innocent sufferers who are unquestionably

entitled to medication and regions inhabited by manipulative drug addicts, liars and criminals. This brings shame to the lives of chronic pain patients and along with shame, this brings frustration in the lack of a legitimating voice. Their uncertain reality is the key suffering in their lives.

4.3-Conclusion

The paucity of available literature on an invisible category like pain and stigma makes us understand the basis of phenomenon and develop an understanding on whatever little is available. Stigmatisation as a process in the lives of chronic pain patients leads to a moribund situation. Negotiation appears to be the only leeway in the dearth of any positive hope. The sense of loss, frustration and shame promulgated by stigmatic reactions from the expert as well as lay communities multiply the suffering to no bounds. The question of seeking an end to suffering is possible in case of complete disappearance of pain. Such a possibility appears bleak as of now. To provide an environment conducive for the respectful sustenance of the sufferers, it then becomes crucial to empathise with the patients. This can be initiated by the institutional corridors of biomedicine and immediate family of the sufferers. These solutions may sound too utopian given the extant codes of conduct which formulate the basis of various institutions rendering help to ameliorate the suffering. Delving into the problems of suffering, issues related to rationality, normality and conformity can make us understand the problem in a better way. For now, instead of proposing solutions which appear too farfetched, it is important to bring the socio-cultural issues which problematise 'chronic pain' into the public glare.

5. Conclusion

Chronic pain, as has been observed during the entire course of discussion, is a multidimensional problem requiring multidimensional solutions. Biomedicine alone is not able to tackle the pain question. Social sciences have attempted to provide a deeper understanding to the issue of pain by taking into account the role of biomedicine and other healing systems, cultural notions regarding pain, the experience of pain, the phenomenological aspect of pain, micro-contexts of everyday life as well as issues associated with economic and polity debates. Medicine's inability to humanely respond to the concerns of its patients in general (Sullivan 1986: 331) makes it difficult for patients subsumed under the ambiguous categories to find out any proper cure or treatment. Pain patients feel that biomedical practitioners routinely delegitimize their experience pressing them to believe that their pain is not real. The feelings of being violated by the practitioners and betrayed by the biomedicine are two very strong points leading to the alienation of sufferers from the medical model. This leads them to shift from the dominant model of medicine to other alternate as well as complementary medicinal systems which promise a holistic understanding of condition.

Chronic pain is one such category which defies the moral codes of any disease/illness primarily for the reasons that pain is neither of them. Rather pain, as far as its biomedical meaning is concerned, is considered as a symptom which signals that something is wrong with the body. This signifies that pain has some biological function. Hence, a category like intractable chronic pain also known as chronic pain syndrome lacking any observable cause or lesion baffles the health practitioners.

Biomedical terminology dominates everyday life too. For instance, a friend while speaking in support of vegetarianism stated that eating an egg does not label us as non-vegetarian (and only 'eggitarian') precisely because of the absence of a visible nervous system to people consuming eggs and thereby assuring him that the egg

which has not yet transformed into a chick is devoid of any painful experiences. In such a case, most of the patients instil their faith in medical interventions which prove futile. At various occasions, as can be observed in previous chapters, patients speak the language of biomedicine in routine life. They explain their suffering in the same too. This primarily can be seen as the influence which biomedicine exerts on the society in general.

Chronic pain patients, in the lack of any visual diagnostic evidence, try looking for reasons for their pain. Their struggle for providing meaning to pain and seeking legitimacy for their condition as well as their selves constitutes the remaining part of their life, till the time chronic pain lasts. In such a situation, it becomes imperative to look for measures which can assist the chronic pain patients in coping up with their suffering.

As per Jackson (2011), social sciences have the potential to act as a tool to ameliorate the suffering of pain patients and those around them. However, it should not be forgotten that various disciplines exist in a hierarchical relationship to each other with sciences being on the top of the ladder for the so called 'rational and objective' approach which relies on experimentation and observation. However, the fact that in case of fields like health and medicine which have a scientific approach, the object of inquiry is not a lifeless entity but human beings who experience, emote and have subjective elements to their understanding, makes it difficult for a reductionist biomedical model to cater to the problems patients experience.

Wellard (1998: 53) mentions in her work the dominance of scientific discourse in western society. The author states that the authoritative biomedical discourses have been created through indulging in scientific discourses which are epitomised in the scientific method of inquiry incorporating 'the ideals of objectivity, reliability, precision and validity, and privilege science over other ways of knowing. This definitely leads to the exclusion of subjective experiences. The author cites Tesh (1990) who states that social sciences which seek to explore 'other' factors relating to chronic ailments (even pain) are viewed as lesser sciences and often treated as 'peripheral' to the central focus of comprehending disease. This difficulty is

heightened in case of pain patients who are an enigma to medical sciences which base their findings on a limited set of principles. Kugelmann (1999: 1669) very aptly states that pain is social, legal, political and economic as well as a medical condition. But because of what counts objective in the contemporary order of things, pain that outlasts the mending of bones and tissue is subject to disbelief.

Bates et al (1997: 1442-1446) advocate an approach which takes into account the cultural context of both the practitioners as well as the patients. They suggest that it can be possible if health care providers act as patient advocates and counsellors besides doing their usual job. In addition, the authors suggest the inclusion of a bio-cultural curriculum emphasizing the mind-body integration in the educational training of all the health professionals. An integrative bio-cultural approach to modify physical impairments and socio-cultural, occupational, economic and health care elements of the life world of pain sufferers can mitigate suffering to a large extent.

Jackson (2011) documents many problems faced by pain patients. She quotes Morris (1991:10) as per whom one of the most significant problem of pain is it's under treatment. One part of this problem is associated to drug trafficking even in case of prescription drugs and henceforth, extremely tight regulation of opioids by the state. Another reasons mentioned by Jackson (2011) comes from her early work in a pain centre where the patients mention the inexperience of pain sensation in case of pain researchers and pain practitioners despite the existing empathy and knowledge. For instance, "I wish that doctor could feel this pain for a day-only for a day, because I wouldn't want *anyone* to feel it any longer than that" (Jackson, 2000).

In developing nations like India, where one may not be able to find any study on chronic pain by social scientists, intractable chronic pain or chronic pain syndrome is an unheard category. In day to day life either people hear complaints of being in pain or experience it themselves or the years pass with no one paying as much of an attention as paid in the west (especially United States). They rely on over the counter medications as self-medication is rampant. This makes us question if the

way chronic pain syndrome is dealt with in the west, is it because of different world views or budgetary constraints faced by developing nations unlike United States?

Pain has its importance and advantages as well more so for the health practitioners. Pain serves physicians as a diagnostic tool. Pain reports are considered authentic when reports can establish causality in illness and injury. Physicians learn to use reports of discomfort as a way to develop diagnoses. Pain can also serve to validate the associated professions. For instance it legitimises the physician's way of treatment. As can be seen in Jackson's (2000) work and other literature on practitioners in chronic pain clinics, it can easily be observed that the amount of interest practitioners take in the treatment and authentication of pain is enormous.

An article in a Science Encyclopedia¹⁸ states that "there are tensions in authentication processes, however, in part because physicians act as certifying authorities or gatekeepers to avenues of compensation and treatment, and in part because they are concerned with proper diagnostics of organic causes of pain." The article states that there is an upsurge in the number of patients of chronic pain in the west but due to the ambivalent nature of chronic pain, as discussed above, it usually falls "outside of the colloquial realm of credibility" and this gradually leads to frustration amongst the health practitioners further leading to hostile relations between the patient and the practitioner (Jackson 2005).

The nociceptive model of pain, which Jackson (2000: 12) describes as the model which focuses on the disease and injury process that trigger the pain rather than focussing on experience of a disordered body which comes under the rubric of illness, is nullified with chronic pain. One can clearly observe the disease-illness dichotomy being used here for explaining chronic pain which further raises the expert-lay dualism thus reinforcing the power relations between doctors and the patients. Also, as the article mentions, 'researchers have either denied that chronic pain is "real", or positioned chronic pain in an ambiguous relationship to acute and organic pain (ibid.). The same article (in Science Encyclopaedia) states,

¹⁸ <http://science.jrank.org/pages/63386/pain-culture.html#ixzz1LZNSAZlg>

“Researchers suggest that pain sufferers can use pain to gain attention and this attention is gained through manipulating interpersonal relations or through receiving certification from compensating institutions such as the state or an insurance firm. This is seen as an inauthentic use of pain, and it sits uneasily in a tacit nexus of a culturally endorsed stoicism and a professional mandate for the appropriate treatment of the individual.” (Science Encyclopaedia)¹⁹

It must have struck in the present work that, at certain places, the terms chronic pain and chronic illness have been used interchangeably. Here, I would like to mention that such a pattern has only been repeated where there was a possibility to use the terms interchangeably. As states Richardson (2005: 45), in essence, the two terms are different from each other. These differences are related to the nature of chronic pain which is invisible, subjective and chronic. Moreover, it is not legitimated by any diagnostic labels either.

A dominance of positivist empiricism as the basis to understand chronic pain limits the way pain is understood. The ‘person’ aspect of the patients is removed from scientific investigations leading to a reductionist approach which looks at patient as an individual who is to be blamed for the suffering. Also, chronic pain patients fall outside the expected ‘norms’ primarily for the reason that they fail to restore themselves to ‘normal’ health. Wellard (1998: 53-54) mentions in her work that for maintaining the norm, surveillance is adopted as one of the most important strategies to monitor patient compliance with the ‘expected norms’. She cites Anderson et al (1989) stating that ‘underlying the desire for normalisation is a drive to ensure people are productive elements in society. So as to maintain the norms, health care workers occupy the role of agents in this quest.

Also, it is essential to look for what makes chronic pain a stigmatized category. The discussion in preceding chapters cites multiple reasons varying from the invisible, chronic, aversive and everyday nature of pain. what one needs to develop is an integrated approach which takes into account the social, psychological and biological elements together to look for solutions necessary for diminishing the suffering and rendering care, support and empathy till the time no permanent relief

¹⁹ <http://science.jrank.org/pages/63386/pain-culture.html>

arrives for chronic pain patients. For this it is essential that a biopsychosocial model is adopted.

The biopsychosocial model, as proposed by many eminent pain researchers, has been an attempt to overcome the limitations of an overtly biomedical reductionist focus, and can be seen as a relatively more appropriate approach for a successful management of the multiple dimensions associated with chronic pain. This is possible by bridging the gap between the disciplinary boundaries of medical knowledge and social sciences. What has not been questioned yet is how is this integration going to be possible with the two streams having completely different world views? The present dissertation does not propose to find a solution for these issues; rather it leaves with certain pertinent questions which are relevant for an empathetic understanding of suffering of pain patients. In conclusion, we can add that the circumstances produced by chronic pain defy all the logic of the sufferers. After examining chronic pain and related issues in detail, it can be concluded that the determination of health and well being is a multi- way process which is not only dependent on practitioner's version but also on society as well as patient's perspective.

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²⁰ The article was obtained through email received from the author, Jean Jackson, at the time when it was still under publication. It was obtained as a word file without page numbers.

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APPENDIX –I

Below is given one such record of conversation from the same social networking site which shows individuals' perceptions regarding being stigmatised and the subsequent experience. All the posts were made a year ago²¹.

Topic: Stigma and Chronic Pain

Chronic Pain Info

Why is it that anyone who so much as mentions the words chronic pain they are looked down upon? I personally think this aspect of chronic pain is one of the most difficult to deal with.

Adam Archie Arcadipane

it is the idea the you are weak. People know what acute pain feels like. they know it can be strong in intensity and disrupting to activities but its goes away, but acute pain does not cause depression, anxiety, loss of self worth, loss of sleep, loss of sex drive and the dozens of other effects that chronic pain causes. Also we can't forget about those of use with chronic pain who take opiates. People hear the word oxycontin or morphine and they immediately assume that we are drug addicts or drug dealers who are going to pill mills and assisting in destroying society. Try and see it from an insensitive person without chronic. They know what pain feels like so they assume what it feels like to hurt, except for a longer period of time. its easy if u think u have an idea of what its like then it is easy to say we are a bunch of addicts, and or drama queens

Chronic Pain Info

²¹ <https://www.facebook.com/topic.php?uid=277614584113&topic=12038>

I can completely relate to what you are saying Adam! I was on just about every schedule II narcotic there was. You name it, I tried it. My family understood but extended members of the family and even friends began to treat me as if I was an illegal IV drug user who contracted AIDS. It is somehow Taboo in our society to have any disease or condition that is not tangible or can't be seen. Unseen pain is as real as the air we breathe. Believe me, I wish it weren't.

Marsha Holderfield

I'm fortunate enough to have my psychiatrist help control my pain. And my family understands that I do have chronic pain, but aren't fans of the medications I take. Suffering with Fibromyalgia, Bipolar Disorder, and anxiety disorder causes me to spend a lot of time at home having no desire to get out of my house. This winter has been one of the hardest on me in many years, although I have pain on a daily basis, some days just trudging thru because things have to be done. Also, I'm grateful that I have a husband who is on disability and is able to still do things like going to the store running errands, etc. But I too am against anyone that looks at us like we just want the meds and should be doing something else like exercising to get better, Yeah, right!!!

Chronic Pain Info

Exercise-out of the question for me right now!

Deb Jaimes

Marsha... I won't even go into all the things going on with me; it's like a grocery list! But I can empathize with you and how it's so hard sometimes just to get thru the day. My physical problems limit my mobility, if I go out for an extended time; I have to use a wheelchair or my walker that has a seat on it. But there are days when just the thought of crawling out of the bed gives me a headache. My husband is also disabled, but does work. When he is home, he takes care of all the errands and housework (which isn't much, we are empty nesters). But when he's not here, the days are long.

Remco Okhuijsen

Hi all, suffering from a chronic bladder pain/ infection. Been on painkillers (several thousand!) for five years, soon 6. I've tried many different forms of alternative healing as well amongst which acupuncture just recently. All without any effect though. I'm open to ANY and ALL suggestions.

Amy Christine Martin

I have become an anti-social person due to my chronic pain and the stigma. I just get tired of trying to explain TOS and RSD and having people look back at me like I am crazy. Or people say well you look really good. UGH, I wish they could have my nerve pain for 24 hours. Do they really think I care how I look? Anyway, I was also tired of people trying to think of jobs I could work when they don't understand I would give anything to work, but can't!!! SO MY POINT IS ~ NO PERSON CAN UNDERSTAND ANOTHERS PAIN!

Deb Jaimes

Yes Amy... some person can and that is the people right here on Chronic Pain because we all share the same pain. Not just whichever diagnosis we have, but the pain of isolation. And isolation is probably the worst thing to have. I have RSD/CRPS and fibromyalgia. So I know what you are talking about when you try to explain what's going on to others who don't have a clue. Even the 'well meaning' ones who think that if you could work again, things would be better. No, they don't have a clue, but maybe they feel just as hopeless as you do. I know my family has had problems dealing with my pain, and I feel that they do feel hopeless as to how to help me. It's a constant battle that we all face, but be sure of this... you are NOT alone... we're here for you!

Sonia Mills

Hi Remco, I know what it is like to have chronic bladder pain/spasms and i also know how doctors can dismiss it as being "not real/imaginary/all in my head" it took me years to find not only a dr that believed the painful spasms were real but one who would also treat it by removing my bladder as well (i had already had a urinary diversion/urostomy done in 2003 but they left my bladder in place and the

pain just got worse) i got so many knock backs in the process which sent my mental health plummeting each time, from my local consultant believing me but refusing to operate cos i would "die on the table" according to them, i went through so many painful procedures attempting to ease the pain but wasn't believed when they didn't bring the relief the drs said they should provide and was on a constantly increasing dose of daily morphine tablets, daily anti spasmodic's (buscopan meant for ibs not bladder spasms but the only one that would help) and tamazepam and extra liquid morphine when the pain was especially bad. It got so bad that by last year i couldn't even leave the house due to the combination of pain and side effects and lack of energy from all the drugs etc but last october i got my life back, i finally got the op i knew i needed which was to remove the main source of the pain my bladder, not possible if you still need your bladder, but i didn't need it and now i have tons more energy than i did and a lot less pain as well. I'm still fighting the pain battle as being less active through the pain/drugs etc only succeeded in speeding up the deterioration in other conditions i have like physical disability and joint problems but compared to how i was i feel like a new woman. Anyway i hope what i wrote is of use to you and if you want to talk more or even want to know what some of the drugs were i tried along the way then please do get in touch. Best wishes Sonia xxx

Sarah Williams

I think one of the reasons people find it hard to understand is that they can't possibly imagine it. I have experienced so much ignorance and lost so many friends because they either don't believe it or don't understand it. Then there's the whole other ignorance when it comes to narcotics.

Erica Organ

What frustrates me is that people that abuse RX medicine, they make it hard for people who have legitimate pain and diagnosis. That is part of the big problem in the United States. Doctors are scared. So patients suffer!!!!

