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## **BIOMEDICINE AND PAIN**

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*Alle mie nonne, Elsa, Giulia, Marisa e Mira che mi hanno spinto a fare un lavoro  
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*Il minimo che io possa restituir loro*



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## Introduction

This dissertation focuses on pain as the object of biomedical knowledge, examining the ways in which pain has been conceptualized and approached in biomedicine as a specific site of investigation. Even if my work is concerned specifically with the ways in which pain is currently dealt with in clinical practice, my dissertation attempts at drawing a much wider and in-depth analysis of the relationships between biomedicine and pain. The topic of research is tackled through several perspectives, engaging a history of ideas, philosophical investigation and ethnographic enquiries. Throughout my work, biomedical knowledge of pain is analyzed in a multi-level perspective, aiming at grasping how different conceptualizations interact between them by contributing to the definition of pain in biomedical knowledge.

The first chapter presents an historical contextualization of what can be regarded as a revolutionary shift in the scientific conception of pain occurred in the second half of the XX<sup>th</sup> century. In 1965, a psychologist and a neurophysiologist, Ronald Melzack and Patrick D. Wall, proposed a new theory of pain mechanisms, the Gate Control theory. Melzack and Wall's novel theorization conceives of pain as the outcome of a complex modulating system influenced by physiological as well as psychological features. This entails the dismissal of the previous conception, i.e. the Specificity theory, which saw of pain as a sensation, such as touch and hearing, endowed with a specific anatomical substrate underlying the transmission of pain from the periphery to the brain. In this framework, pain was the result of a noxious stimulation at a

peripheral level, directly and faithfully transmitted to the brain. Gate Control theory shows instead that such a direct and proportional relationship between tissue damage and pain is unaccountable for by physiological findings, and supports the hypothesis, confirmed by clinical findings, that the link between lesion and pain is highly variable.

In neurophysiology, the Gate Control theory stressed on the crucial integrating role played by the central nervous system (CNS), by leading scientists to focus on pain processes at a central level. The most recent development of Gate Control theory, Melzack's body-self neuromatrix, advances a framework to explain at a central level not only pain mechanisms, but the neural basis of bodily perception. Anyway, the "temptation of specificity", i.e. the attempt to localize pain, remains a leitmotiv in the scientific research on pain; in this regard, the current re-formulation of Melzack's model, the Pain Matrix, which describes pain as concurring with the activation of precise neural areas, is emblematic.

However, the major contribution of Gate Control theory to the re-conceptualization of pain is not to be found in the neurophysiological domain, but more in general in the biomedical one. Melzack and Wall's theory of pain mechanisms has indeed provided the "scientific ground" for the constitution of a new specialty of medicine, i.e. pain medicine, constituted in the US in the second half of the XX<sup>th</sup> century and primarily devoted to the study and the management of pain.

In 1979, the Association of the Study of Pain (IASP), arising from the pain medicine movement, puts forward what is still the most influential definition of pain.

The change of perspective on the phenomenon is expressed in IASP's definition of pain as "an unpleasant sensory and emotional experience associated to an actual or potential tissue damage or described in the terms of such a damage." The extent of the renewal of pain's conception is remarkable since IASP acknowledges pain as a complex multidimensional entity and not, as previously maintained, a compound of sensory features -pain perception- and emotional ones -pain reaction-.

The historical contextualization of IASP's definition witnesses for its pragmatic vocation, i.e. representing a useful and shareable tool for specialists working in the field of pain. In this regard, the primary scope of the definition's proponents is the recognition at a clinical level of the reality of all pains, no matter whether an organic damage is detected or not. The stress on the subjectivity of pain, stated by its definition as an experience, clearly aims at remarking the individual epistemic authority in relation to the presence of pain; nevertheless, as my analysis shows, this attempt is undermined by IASP's classification of those pains not related to a tissue damage as psychogenic. In my perspective, this is due to an ongoing attitude characterizing biomedical approach to pain grounded on a dualistic view of pain's causation which fails to appreciate the complexity of the phenomenon. This approach is particularly clear in the biomedical approach to pathological pain, specifically the so-called psychogenic pain and chronic pain. The investigation of the ways in which biomedicine deals with these objects, engaged with in chapter II and III, is at the core of my thesis.

Psychogenic pain is a label used to define those pains which are supposed to be caused by psychopathological factors; in chapter II, an historical overview of the main psychological conceptions of “psychogenic pain” from the second half of the XX<sup>th</sup> century is presented. The Diagnostic and Statistic Manual of Mental Disorders’ (DSM) classifications of “psychogenic pain” are discussed in relation to the wider psychiatric debate on the supposed psychopathological mechanisms underlying these pains. Through a philosophical investigation, the validity of the last categorization of “psychogenic pain” (DSM-IV), *Pain Disorder*, is questioned, and it is concluded that *Pain Disorder* classification cannot be the ground for a valid psychiatric diagnosis. This categorization is strongly disputable since it does not provide positive criteria to identify a precise clinical entity and, notwithstanding the efforts to dismiss a dualistic conception of painful conditions, it ultimately fails in this attempt, being mainly a categorization based on the exclusion of organic findings accounting for the pain.

The inability of the biomedical framework to provide a coherent classification of problematic painful conditions appears even more evident and troublesome when dealing with chronic pain. Chapter III is entirely devoted to the development of this issue, i.e. the biomedical approach to chronic pain as a disease entity. Chronic pain, generally defined as the pain that lasts longer than the usual course of an acute injury or disease, represents a major challenge for biomedicine since its pathological status is not usually defined by the identification of a morbid process underlying pain persistence, but on the basis of the consequences that it brings about on the

individuals' lives. The recognition of this entity's pathological status is at the core of pain medicine's movement, which arises as a pluridisciplinary specialty practiced by several specialists working in the field of pain: anesthesiologists, such as John J. Bonica who is also the leader of pain medicine's movement, neurophysiologists, psychologists and psychiatrists. The presence of such different perspectives leads also to different co-occurring interpretations of chronic pain as a disease. (See Baszanger, 1998) The first section of Chapter III deals with the constitution of chronic pain as a disease entity in pain medicine, by presenting the development of this notion in the different editions of Bonica's textbook, *The Management of Pain*. The recognition of the role played by psychological factors in chronic pain's production and maintenance is a fundamental issue which marks the most relevant distinctions between different orientations towards chronic pain in pain medicine. Among the interpretations given to persistent pain conditions, and the related disease' conceptions, the notions of "chronic pain syndrome" (CPS) and "abnormal illness behavior" (AIB), are analyzed as some of the most controversial. These concepts represent attempts to account for problematic conditions characterized by a discrepancy between the sufferers' pain behaviors and the detection of organic damages accounting for pain. Beside the epistemological issues involved in these categorizations, i.e. their inability to define precise disease entities, both CPS and AIB result are emblematic of the troublesome status of chronic pain as a disease in a socio-economic perspective, e.g. in relation to disability claims. The impairment brought about by living with persistent pain, when unaccounted for by some



“objective” tool to assess the presence of pain, represents a noteworthy issue in the social and health systems’ agendas, above all when considering the always increasing dimensions of the problem.

The troublesome acknowledgment of chronic pain as a disease is further witnessed by the classification of chronic pain in the International Disease Classification (ICD) by the World Health Organization (WHO). In ICD-10, when chronic pain is not related to a specific body location, it appears somehow “unclassifiable”: while *Chronic Intractable Pain* resembles more a rag-bag category to collect poorly understood painful conditions than a disease classification, psychogenic pain is classified along the lines of the DSM without any further specification. This makes WHO’s manual’s categorization of chronic pain unfulfilling and strongly confirms the liminal positioning of chronic pain in biomedicine. (See Jackson, 2005)

The multifaceted character of chronic pain, in addition to its frequent comorbidity with psychopathological issues, leads to a “scientific uncertainty” on the status of chronic pain as a disease. This situation is particularly insidious for biomedicine because it concerns pain’s causation, which keeps on being addressed in dualistic terms, i.e. chronic pain may be caused either by organic factors or by psychological ones. This approach, dismissing also the scientific evidence indicating that the only viable account for chronic pain can be given in a multi-causal psychological and physiological framework, is well-represented by the biomedical approach to the comorbidity between chronic pain and depression. The relation between the two

entities is both epistemologically problematic and clinically relevant, since many chronic pain conditions today are treated with antidepressants.

The bounds separating organic and psychogenic interpretations of chronic pain are though far more complex than in what is seen as the traditional Cartesian version of the dualism between mind and body, and involve social and practical matters. The gap between psychogenic and organic pain, affecting the lives of many chronic pain sufferers, is retraceable in issues which go beyond dichotomous conceptualizations and concern practical features such as the hyper-specialization of biomedical system which reinforces the narrowness of biomedical approach to chronic pain.

In the fourth chapter of my dissertation, the findings of the theoretical investigation of biomedical knowledge of pain are discussed with a focus on a specific chronic pain condition, fibromyalgic syndrome (FMS). Fibromyalgia, a condition characterized by chronic widespread pain and other debilitating symptoms such as fatigue, cognitive, sleep and mood disturbances, is emblematic of the problematic status of chronic pain in biomedicine. Even though FMS is treated in Rheumatology in virtue of its predominant symptom, i.e. pain localized in the musculo-skeletal system, its disease status is highly debated. The troublesome acknowledgment of this condition is due to several factors: i) fibromyalgia is a syndrome, i.e. it is characterized by a constellation of very diverse symptoms, including psychological issues such as anxiety and depression; ii) fibromyalgia's aetiopathological mechanisms remain mostly unknown, even if today this condition is conceived as part of a much wider spectrum of elusive conditions such as chronic fatigue syndrome and irritable bowel syndrome as a

central sensitization syndrome, i.e. a dysfunction of the CNS. Moreover, fibromyalgia, whose diagnosis is mainly based on the exclusion of other conditions and not on positive criteria, is not curable, but it is treated mainly with antidepressants, especially serotonin-norepinephrine re-uptake inhibitors (SNRIs) and anti-convulsants, in addition to painkillers.

My investigation of fibromyalgia, aimed at unraveling the ways in which this entity is currently defined as a pathological condition in the clinical practice, is pursued through an in-depth ethnographic enquiry. A first part of the research is grounded on a participant observation of the clinical interactions between patients and physicians in the Rheumatology Unit of a local clinic. The ways in which fibromyalgic syndrome is actually defined in the clinical practice are investigated and discussed; the conclusion is that what biomedical knowledge labels as fibromyalgia is not a single object, but many objects, ranging from purely psychological conceptualizations of this condition to mixed psychological and organic ones. The common feature shared by these conceptions is that fibromyalgia is a pathological state, but an ultimate understanding of it as a specific clinical entity remains debated. The research question, i.e. how fibromyalgia is defined as a pathological entity, is further investigated in the last section of chapter four, by looking at sufferers' experiences of living with this condition. Patients' illness accounts are elicited through the employment of photographic tools, considered particularly adequate in order to tackle such an elusive experience as that of pain. In-depth interviews are conducted with four patients encountered during the development of a complementary therapeutic

program for fibromyalgic patients by using photographic representations of pain coupled with written questions focusing on the patients' experiences. The outcomes of patients' photographic narratives of their living with fibromyalgia are presented and analyzed. The issues identified as crucial in the definition of chronic pain as a disease throughout the course of my work, such as pain's causation, the boundaries between mental and physical pain, and the definition of chronic pain as a disease, clearly emerge as part of the individual experiences of the sufferers as well as pivotal features characterizing the biomedical object labelled fibromyalgic syndrome.

In the Conclusion, the main outcomes of my analyses of current biomedical understanding of pain are recalled and the several problematical issues affecting biomedical approach to pain, especially to chronic pain, are connected in a wider framework. Moreover, the methodology employed is discussed and the potential future development of my research are presented.

The results of my investigation indicate that the main source of the problematic acknowledgment of pain as a complex multidimensional phenomenon and the related issues thwarting an adequate approach to chronic pain conditions in biomedicine must be found in the sectioning and localizing structure of biomedical system. In this sense, pain remains an actual challenge to biomedicine whose engagement is unavoidable.

## Chapter 1

### PAIN AS THE OBJECT OF SCIENTIFIC KNOWLEDGE

#### 1.1. *The “discovery” of pain as a complex multidimensional entity*

##### 1.1.1 *Introduction*

In 1965, an article entitled *Pain mechanisms: A New Theory* by psychologist Ronald Melzack and neurologist Patrick D. Wall appears in *Science*. The extent of this neurophysiological theory’s novelty stated in the subhead, the proposal of the existence of a gate control system which “modulates sensory input from the skin *before it evokes pain perception and response.*” (Italics added)

Gate Control Theory of pain aimed at supersede previous conceptions of pain mechanisms, especially the specificity one. When Melzack and Wall put forward their theory, the specificity model was taught in almost all medical schools and it was generally believed that pain problem had almost been solved (Melzack, Wall, 1984: 196), even against some clinical observations. The most challenging evidence was the variable link between injury and pain, which strongly contrasted the supposed fixed relationship between the intensity of noxious stimulus and pain perception postulated by specificity model (See Melzack, Wall, 1984: “Pain and injury: the variable link”). As Melzack and Wall will later remark, there were indeed many painful

conditions characterized by pain without lesion or lesion without pain, representing an actual “puzzle of pain”<sup>1</sup>.

In their article, Melzack and Wall discuss previous neurophysiological theories of pain, specificity and pattern theory<sup>2</sup>, highlighting their weaknesses and strong points. Gate Control is presented then as the model which can finally answer the questions about pain left unsolved.

Even if nowadays neurophysiological textbooks do not deserve much space to Melzack and Wall theory, the relevance of this renewed conception of pain mechanisms is related to a wider change of perspective on pain which this theory has brought about. In the present section, I will try to highlight precisely this issue. My focus on Gate Control theory of pain is also motivated by the role that Melzack and Wall theory has played in the constitution of pain medicine, and, more generally, in the clinical practice, which is related to the acknowledgment of pain as a complex multidimensional entity. Moreover, Melzack and Wall theory of pain mechanisms seems to be the scientific basis on which it has been possible to put forward the first scientific definition of pain to which nowadays almost everyone in the scientific field as well as in the humanities, refers to<sup>3</sup>. In the current section this issue will be discussed by referring to new approaches in pain management related to Gate

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<sup>1</sup> In their 1984 book, Melzack and Wall define the situation of neurophysiological knowledge of pain the “puzzle of pain”

<sup>2</sup> Under the label “pattern theories” Melzack and Wall group a set of neurophysiological conceptions elsewhere labeled as “intensive theory”. See for example Bonica, 1992,I: 7

<sup>3</sup> The definition of pain I refer to has been put forward in 1979 by the International Association of Pain and will be analyzed in the next section of this chapter

Control's renewed conception of pain mechanisms. Moreover, as Baszanger (1998) remarks, Melzack and Wall's theory has represented a pivotal theoretical tool in the constitution of the rising field of pain medicine, by providing a common ground for different disciplines, e.g. anesthesiology, neurophysiology, psychiatry concerned with the treatment of painful conditions. This issue will be discussed in chapter III in relation to the biomedical approach to chronic pain.

In this section, I introduce and analyze the shift from the specificity theory to gate control in order to discuss the main issue that this change of view on pain has brought to the forefront, the acknowledgment of pain as a complex multidimensional object. More specifically, I will focus on two aspects of this matter which I consider to be crucial in the novel conception of pain -including chronic pain- as a biomedical object: the first one is Gate Control's denial of a direct and straightforward relationship between tissue damage and pain and the second one is the appreciation of the role played by psychological features in pain.

#### *1.1.2. Specificity theory: pain as a specific sensory system*

In this paragraph I will sketch a brief history of pain theories in XIX<sup>th</sup> century by focusing in particular on the specificity model of pain mechanisms; my aim is to trace a framework for an adequate comprehension of the main issue I am concerned with, the shift of perspective on pain brought about by the formulation of Gate Control theory of pain.

My primary source is Roselyn Rey's *History of Pain* which is the most corroborated and recent historical work on pain; as a secondary source, I have mainly referred to Hodgkiss (2000).

As highlighted by Rey (1995), "as far as pain was concerned, thinking remained within the global framework of 'specificity theory' throughout the whole 19<sup>th</sup> century". (Rey, 1995: 135) Specificity model -broadly conceived- indicated the existence of a sensory system responsible for pain sensation, entailing therefore the existence of specific anatomical substrates subserving the transmission of pain sensation from the periphery to the brain.

The idea that pain was a sensation with a specific sensory apparatus had already been postulated in the antiquity by Galen and Avicenna. A prefiguration of XIX<sup>th</sup> century specificity model of pain mechanisms is usually dated back to René Descartes 1664 treatise *L'homme*. Here, the French thinker described the functioning of the body-machine and presented the well-known image of pain pathways (see fig.1): when an external stimulus such as fire was in contact with the skin, the movement of fire and skin's particles had the power to pull a thread (the nerve filament) connecting the skin to the brain "just as by pulling at one end of a rope makes to strike at the same instant a bell which hangs at the other end." (Descartes, 1664. Quoted in Melzack, 1977: 127) The conception of pain as a "ringing bell" indicating the presence of a peripheral lesion in the body was at the core of later formulations of the specificity theory; the common aim of physiological research



postulating the specificity of pain sensation was the individuation of specific anatomical substrates responsible for pain sensation.



Fig.1 Descartes' concept of pain pathway<sup>4</sup>

XIX<sup>th</sup> century, which began with Bell and Magendie's discovery of the specialization of the functions of anterior and posterior roots of spinal nerves<sup>5</sup>, saw also the rise of physiology as an experimental science. At that time, a major issue for physiology was the different qualities of sensory modalities, i.e. what distinguished olfactive, visual, gustative, auditive, tactile (and painful) sensation. In order to address this issue, in 1835 the German physiologist Johannes Müller introduced the

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<sup>4</sup> Descartes, *L'Homme* (Paris, 1664). In Melzack, Wall, 1965: 972

<sup>5</sup> The history of Bell and Magendie's discovery in 1822 of the different functions of anterior and posterior roots of spinal nerves, the motor and sensory one is well-known. The paternity of this pivotal discovery has generated in those years a huge quarrel which has been told also by Claude Bernard. Even if Charles Bell had first the idea for an experimental procedure to dissociate sensibility and movement, his hypotheses were mainly deductive since that he made experiments on dead animals in which therefore sensibility could not be appreciated. Francois Magendie conducted indeed experiments on living animals which caused him also noteworthy critiques. See Rey, 1995: 182-192

“law of specific nerve energies” claiming that different sensory information on external objects were transmitted to the brain through sensory nerves carrying specific energies for each sensation. The specificity of sensations carried by nerves was accounted by Müller’s hypothesis of there being a particular relationship between the nerve and the related stimulus. The physiologist did not indicate a particular anatomical site for these energies, but simply postulated the specificity of sensations on the basis of a particular property of sensory nerves themselves.

Müller’s conception is often viewed as the first formulation of the specificity theory; nevertheless, it is to be stressed that his view is not grounded on experimental physiology, but is related to a vitalistic framework in which the scientist saw physiological processes. As highlighted by Rey, Müller’s conception entailed indeed a metaphysical view of neural structures such as nerves. This framework will lack in later formulations of specificity theory such as Von Frey’s, aimed at detecting anatomical substrates accounting for the specificity of sensations.

The peculiarity of Müller’s theory lied in his conception of sensation as “the communication to the sensorium, not of the quality or state of the external body, but of the condition of the nerves themselves (...) We do not feel the knife which gives us pain, but the painful state of our nerves.” (Müller, 1838: 766. Quoted in Hodgkiss, 2000: 79) As both Rey and Hodgkiss highlight, Müller’s theory of specific nerve energies entailed the equivalence of sensations raised by internal and external causes; according to Müller, what was crucial in sensation was not the external stimulus but the nerves themselves. This conception of the specificity of sensation

implied also that, in Müller's view, there was no distinction between internal "imaginary" pains and "real" ones. In chapter II, I will discuss this issue -the distinction between "psychogenic" and organic pain- as a crucial aspect of the biomedical approach to pain.

Like most scientists at that time, Müller did not consider pain as a sense in its own right but as a modality of touch, elicited by particularly intense stimulations. Nevertheless, physiologist's conception of pain phenomenon was far more complex than that, insofar as it acknowledged the influence on pain perception of individual aspects such as the subject's attention and her previous experiences.

XIX<sup>th</sup> century was also the period of great discoveries in the field of anesthesia. In 1806, Seturner isolated morphine from opium by providing an important mean to treat pain. In 1846, Morton made the first public demonstration of ether's anesthetic properties stimulating a huge debate in the Académie de Sciences on the employment of stupefying gas in surgery. The relationship between the discoveries in the field of anesthesia and scientific knowledge of pain would deserve a closer examination which is beyond the scope of my work. One can have a look to Rey's history of pain in XIX<sup>th</sup> century, which focuses on this topic by highlighting parallel development in neurophysiological conception of pain mechanisms and the discoveries in the field of anesthesia. (See Rey, 1995: 143-182) For the purpose of the present section, it is sufficient to recall that experimental findings obtained through the observations of selective desensibilization in anesthetized patients supported the idea that sensibility to pain had to be distinguished from that to the

other senses. In 1858, physiologist Moritz Schiff showed through experiments based on sections of the spinal cord the independence of the sense touch and that of pain; at the end of the century scientists Blix, Goldscheider and Donaldson confirmed this finding by individuating separated spots in the skin responding selectively to warm, cold and pressure.

A detailed topography of tactile and pain spots, and therefore a proof of the anatomical specificity of pain, is due to the work of physiologist Max Von Frey. At the end of the century, the physiologist invented the aesthesiometer, an instrument of precision aimed at measuring stimulus intensity in a very restricted area which allowed him to distinguish between pressure and pain points. In particular, Von Frey noticed that pain was perceived when the stimulus went beyond a certain threshold or reached deeply located neural structures. Von Frey's experimental findings brought him to the conclusion that pain was not an altered sense of touch but that it resulted from the stimulation of specific organs. Receptors responsible for pain were then identified as free nerve endings associated to specific nerve fibers. Von Frey's theory is conceived as the acme of physiological theories seeing the specificity of pain sensation as due to the presence of specific anatomical substrates. This theory has remained the leading theory of pain mechanisms until the introduction of Gate Control theory.

As Rey maintains (Rey, 1995: 137), specificity theories, aimed at indicating particular conditions necessary for pain production, have been crucial in the development of the understanding of pain phenomenon. Nevertheless, in these

conceptions, the correlation between anatomical substrates and pain sensation was often interpreted as an explanatory principle, reducing therefore pain to a mere response to the stimulus.

The main competing model to specificity one was the so-called intensive theory. This conception of pain mechanisms, already implicit in the Aristotelic concept of pain, saw pain as the result of an excess of tactile stimulation; this model was explicitly formulated in 1874 by Wilhelm Erb (Erb, 1874). Erb thought that every stimulus could elicit pain sensation if it went beyond a certain threshold. In 1894, physiologist Goldscheider, who had previously sided for specificity theory, concluded on the basis of some evidence contrary to Von Frey's model that pain could be better accounted by intensive theory. The straightforward relationship between stimulus and pain postulated by the specificity theory could not account for phenomena such as the exacerbation of pain upon the repeated application of a stimulus, the delay in the appearance of pain following the application of a pressure stimulus, and, finally, the existence of "transitional" situations in which the sensation of pressure sometimes turned into that of pain.

Goldscheider indicated the stimulus intensity and central summation mechanism as two main determinants of pain. Goldscheider's theory saw particular patterns of nervous impulses evoking pain as the result of a summation of sensorial stimuli afferent spinal cord dorsal horn. Pain arose when a critical level was exceeded because of an excessive stimulation of thermal or tactile receptors or in those pathological conditions enhancing the summation of normally non-noxious stimuli.

### *1.1.3 Melzack and Wall's critique to specificity theory*

Melzack and Wall synthesize the specificity theory as the conception that proposes the existence of a “mosaic of specific pain receptors in body tissue” (Melzack, Wall, 1975: 971) which project noxious stimuli to a pain center located in the brain. Therefore pain is seen here as a specific sensory system compounded by its own central and peripheral apparatus: pain receptors -which are, as Von Frey postulated, free nerve endings- whose impulses are carried by specific fibers to a pain center in the brain.

In Melzack and Wall's view, specificity theory's physiological specialization -the existence of specialised receptors which respond “only to intense, noxious stimulation of the skin”- is grounded on a physiological evidence and has therefore to be retained. On the other hand, talking about “pain receptors”<sup>6</sup> implies also a psychological assumption which has, instead, to be dismissed. The problematic psychological postulate of the specificity model is that of “a direct connection from the receptor to a brain center where pain is felt” (Melzack, Wall, 1965: 971). In the specificity framework, pain is conceived as the outcome of the transmission of an information selected at the receptors' level and directly transmitted to the brain. The main authors' concern in relation to such a conception of pain mechanisms is that this representation entails a more general conception of the nervous system as

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<sup>6</sup> The anatomical postulate implies that each receptor is morphologically specific for a sensory modality but it has never been confirmed by anatomical findings

grounded on a “fixed, direct-line communication (...) from the skin to the brain.”

(Ibidem)

In their article (1965), Melzack and Wall provide a series of arguments against the specificity model on the basis of contrary physiological, clinical and psychological evidence. First of all, even though it is acknowledged that the somesthetic system is specialized, there is no proof that the stimulation of particular anatomical substrates must always elicit pain or that pain sensation is due to the stimulation of cells responding only to noxious stimuli while “the outputs of all other cells are only background noise” (Melzack, Wall, 1965: 972). Furthermore, clinical evidence derived from pathological states such as causalgia (a severe burning pain resulting from the lesion of a peripheral nerve), phantom limb pain (the pain felt in a limb that has been amputated) and peripheral neuralgia (the pain resulting from peripheral nerve infection or a degenerative disease) provide indeed a “dramatic refutation of the concept of a fixed, direct-line nervous system” (Melzack, Wall, 1965: 971), as the failure of surgical lesions of peripheral and central nervous system in abolishing permanently these pains<sup>7</sup>. As the authors highlight, these types of pain may first appear as symptoms of tissue damage, but then they may spread, increase and persist; however, the pain may become worse than that associated with the original

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<sup>7</sup> As reported by Rey, these pathological painful conditions were encountered mainly by war surgeons such as Weir Mitchell during the American Civil War and René Leriche during the First World War. The “abnormality” of these pains which appeared temporally and spatially unrelated to wounds as well as the ineffectiveness of ordinary treatment in dealing with these conditions were striking. Beside these evidences, psychological consequences of these pains on sufferers pushed war surgeons to criticise traditional explanation of pain by highlighting the complexity of the phenomenon. See Rey, 1995: 227

injury. In addition, clinical data showed that pain could be triggered also by non-noxious stimuli and spread in areas where no pathological processes existed or without any recognizable stimulus. In hyperalgesic skin areas, pain could also occur “after long delays, and continues long after removal of the stimulus.” (Ibidem) In this sense, the authors maintain, these pains become maladies in their own right.

In addition to physiological and clinical evidence, the authors argue that the so-called psychological postulate of the specificity theory -the conception of a “direct, invariant relationship between stimulus and sensation”- (Melzack, Wall, 1965: 971) is totally rejected by psychological evidence. A proportional relationship between stimulus and pain may be obtained indeed only by focusing on pain experimentally produced: laboratory conditions, in fact, prevent central nervous system’s activities which are always present in the common experience of pain. The authors argue that it is clear instead that “the amount and quality of perceived pain are determined by many psychological variables in addition to the sensory input” (Melzack, Wall, 1965: 972); the link between stimulus intensity and pain perception is so variable that intense noxious stimulation may turn out not to produce pain at all, as in the well-known case reported by the authors of American soldiers at Anzio. During the Second World War, war surgeon Henry Beecher had the occasion to observe American soldiers who, fatally wounded, denied to feel any pain and even refused medications; this strange behavior could be explained because of the soldiers’ excitement at having escaped alive from the battlefield. Beecher concluded therefore that “there is no simple relationship between the wound *per se* and the pain



experienced. The pain is very largely determined by other factors, and of great importance is the significance of the wound". (Beecher, 1959: 165. Quoted in Melzack, Wall, 1965: 35) Following these and other experimental observations, Melzack and Wall stress indeed the relevance of psychological factors in pain perception, whose role will be also neurophysiologically represented in the Gate Control Theory of pain.

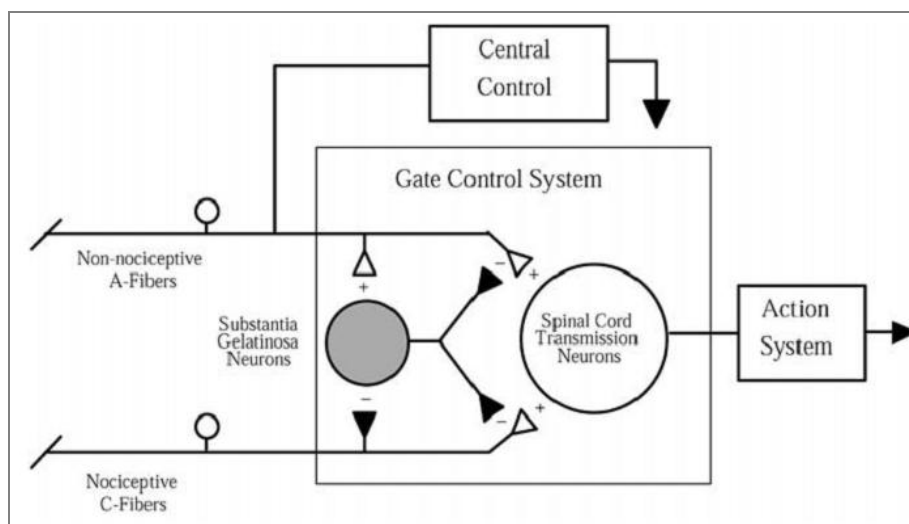


Fig. 2 Gate Control theory of pain<sup>8</sup>

#### 1.1.4 From the specificity theory to the Gate Control<sup>9</sup>

Gate Control theory conceives of pain as an ongoing process in which the whole central nervous system (CNS) has an active role by integrating afferent, upstream processes with downstream modulation from the brain. The perception of pain is thus

<sup>8</sup> In Melzack, Wall, 1965, p. 975

<sup>9</sup> For a contextualization of the shift from Specificity theory to the Gate Control theory of pain in the wider scenario of neurological and physiological development, see Rey, 1995

the outcome of a complex system of modulation of the original stimulus composed by different factors, both physiological (fibers activity) and psychological (attention, prior experience).

The key proposal of Gate Control theory is the existence of a system consisting of cells located in the spinal cord called the substantia gelatinosa that modulates the afferent patterns *before* they influence the T-cells<sup>10</sup>, whose activity is responsible for pain experience and response. The gate system is influenced by the activity of three different pathways: small diameter fibers, large diameter fibers and the central control. While activity in small fibers tends to enhance the transmission of noxious stimuli by “opening the gate”, the activity of large fibers inhibits it; moreover, the activity of a specialized system of “large-diameter, rapidly conducting fibers (Central Control Trigger)” (Melzack, Wall, 1984: 227) activates selective cognitive processes by way of descending fibers exerting control over the original sensory input. Once the integrated firing-level of T-cells exceeds a critical level, it triggers a sequence of responses by the “action system” that represents what is commonly seen as pain response and pain sensation.

Melzack and Wall theory therefore claims that “the presence or the absence of pain is determined by the balance between sensory and central inputs to the gate control system”. (Melzack, Wall, 1965: 977) The integration of ascending and

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<sup>10</sup> T-cells are particular type of cells located in the spinal cord responsible for the transmission of the information to the brain

descending processes is acted by central neural mechanisms *before* somatic input evokes pain perception and response.

Gate Control theory's core proposal of the existence of a modulating gate control system leads to a profound change of perspective on the role played by different factors involved in pain, which deeply influences the scientific conception of the phenomenon. The renewed framework of pain mechanisms presented by Melzack and Wall promotes a shift from the periphery to the centre by stressing the crucial role played by the CNS in integrating different factors modulating pain perception. As Melzack will later remark, one of the most important contributions of Gate Control theory is having forced "medical and biological sciences to accept the brain as an active system that filters, selects and modulates inputs." (Melack, 1999: 123) Whereas specificity theory was mainly concerned with receptors seen as responsible for "the abstraction or selection of the information concerning the stimulus" (Melzack, Wall, 1984: 203), Gate Control theory emphasizes the role of the CNS in integrating physiological and psychological features modulating the original stimulus.

In Gate Control model, psychological factors, which were previously considered solely as reactions to pain sensation<sup>11</sup>, are conceived instead as integral aspects of pain processing. The revolution brought about by Melzack and Wall is that of describing a system accounting for the complexity of pain by including also the action of psychological factors from the beginning of the process producing pain. In Melzack and Wall's model, cognitive factors such as "past experience, attention and emotion

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<sup>11</sup> This issue will be discussed in next section in relation to pain sensory and emotional aspects

may influence pain perception and response by acting on the spinal gating mechanism. Some of these psychological activities may open the gate while others may close it.” (Melzack, Wall, 1984: 247)

In 1968, Melzack and neurologist Kenneth Casey propose a neurophysiological model describing different psychological dimensions of pain: sensory-discriminative, motivational-affective and cognitive-evaluative. In this perspective, cognitive activities such as cultural values, anxiety, attention and suggestion have the ability to “act selectively on sensory processing or motivational mechanism” so that sensory input is “localized, identified in terms of its physical properties, evaluated in terms of past experience, and modified *before* it activates the discriminative or motivational systems.” (Melzack, Dennis, 1978: 10)

The acknowledgment of the powerful action of cognitive activities in modulating the original stimulus turns also nociceptive input into one of the different variables in the whole system. Noxious stimulation “produces neural signals that enter an active nervous system that (...) is already the substrate of past experience, culture, anxiety and so forth.” (Melzack, Dennis, 1978: 1) In this way, Gate Control theory provides also an explanation for the so-called puzzle of pain, i.e. the highly variable link between tissue damage and pain perception. The constant modulation of the original stimulus acted by the gate system entails the fact that even when the pain is caused by a tissue damage, the output of the elaboration of the information is never predictable only on the basis of the intensity of the stimulus applied. The lack of

proportion between noxious stimulus intensity and pain is so wide that there may even be pain perception without nociception.<sup>12</sup>

The psychological postulate of specificity theory assumed that the presence of physiological activity -a noxious stimulus eliciting somatic pain receptors- triggering the transmission system was enough in order to have a pain experience (a psychological state). Recalling Descartes' representation of pain phenomenon<sup>13</sup>, it appears that the bell (pain) rings in the brain only when the toe is put on the fire (external stimulus) causing a lesion; this representation entailed therefore almost a coincidence between tissue damage -and of its extent- and the pain perceived, on the basis of a supposed proportional and fixed relationship between the stimulus and pain. Gate Control theory challenges this conception of pain as "simply a function of the amount of bodily damage alone" (Melzack, Dennis, 1987: 2), forcing to reconsider it as "a perceptual experience whose quality and intensity are influenced by the unique past history of the individual, by the meaning he gives to the pain-producing situation and by his 'state-of-mind' at the moment." (Melzack, Wall, 1984: 50-51)

Melzack and Wall explicitly put forward this change of perspective on the phenomenon by claiming that pain cannot be considered anymore either as "a single ring of the appropriate central bell" or as "a single sensation produced by a specific stimulus" (Melzack, Wall, 1965: 976), but as a category of complex experiences.

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<sup>12</sup> The term has been put forward in 1903 by Sherrington. Nociception is defined today as "the detection of tissue damage by specialized transducers attached to A delta and C fibers", the nociceptive fibers. See Loeser, Melzack, 1999: 1607

<sup>13</sup> See fig. 1, p.5

Such a conception of pain as a multifaceted entity compounded by sensory and emotional aspects will ground the definition of pain given in 1979 by the International Association for the Study of Pain (IASP). The next section of the present chapter will look at this definition and discuss its critical aspects.

#### *1.1.5 New approaches in pain management*

As Melzack (1999) highlights, the reception of Gate Control theory in the scientific world was remarkable and generated strong debates between researchers working in field both aimed at criticizing the theory and at supporting it. From the mid-1970's Melzack and Wall theory of pain mechanisms was received and presented "in almost every major textbook in the biological and medical sciences."(Ibidem) However, sociologist of medicine Baszanger claims that, in general, medicine did not seem to be interested in the outcomes of Gate Control theory of pain; from a review of internal medicine's textbooks, Baszanger concludes that the reception of Gate Control theory in the medical domain can be traced back only to the beginning of 90's. At the same time, though, Melzack and Wall's theory had a noteworthy reception in the rising field of pain medicine. As Baszanger argues in her work on the constitution of pain medicine, Gate Control theory of pain mechanisms opened the way for a revolutionary change of perspective on pain both on a conceptual level and on a practical one. In the first place, Melzack and Wall's theory forced a deep change of orientation in the management of pain. Differently from a surgical approach devoted to the interruption of painful sensation by cutting or destroying pain pathways, Gate Control model indicated instead that pain perception may be decreased or at least

modulated through the enhancement of the organism's physiological control systems by influencing fibers' activity in order to close the gate. Furthermore, the discovery of the fact that cognitive activities such as attention and suggestion could influence pain by acting at the earliest level of the sensory transmission led also to the idea that psychological techniques -such as operant-conditioning, biofeedback, hypnosis, relaxation, cognitive coping strategies, and so on- could be employed in order to achieve pain control. Already in their 1965 article Melzack and Wall suggested therapeutic implications of Gate Control, such as beneficial effects that could be achieved by "selectively influencing the large, rapidly conducting fibers" and "by decreasing the small fibers input." (Melzack, Wall, 1965: 978) The ways in which the modulation of the original input could be achieved were indicated more precisely by the authors in their 1984 *The Challenge of Pain*: i) the employment of anesthetic blocking, ii) low level stimulation activating large fibers inhibiting therefore the transmission of the noxious input from peripheral fibers, iii) intense stimulation activating "brain-stem mechanisms that exert an inhibitory influence on the spinal gate-control system and at higher synaptic transmission levels" (Melzack, Wall, 1984: 299), and iv) the stimulation of descending control systems through electrical stimulation or the employment of certain drugs.

Moreover, as Baszanger points out, Gate Control theory of pain mechanisms clearly indicates that painful conditions may be managed in different ways, both through psychological techniques and physiological ones; the integration of these approaches will be indicated by pain medicine's leader, John J. Bonica, as the proper

one in dealing with problematic painful conditions against which traditional therapeutic means had been ineffective.

#### *1.1.6 Gate Control theory today*

The acknowledgment of the fundamental role played by the CNS in pain processes opens the way to the understanding of complex painful conditions such as phantom limb pain and persistent pain. In a 1999 article, Ronald Melzack suggests that such phenomena may be accounted for by postulating the existence of a brain neural network, the *body-self neuromatrix*. The body-self neuromatrix is seen as responsible for the integration of different inputs which “produce the output pattern that evokes pain.” (Melzack, 1999: S121) The action of this system, as postulated by Melzack, goes well beyond the integrative function previously ascribed to the CNS eliciting pain sensation: according to the author, the body-self neuromatrix is a “genetically built-in matrix of neurons” (Melzack, 1999: S123) which is responsible for the perception of all the qualities that we normally feel as coming from our body. According to Melzack, also our perception of the body as a unity and its identification with the “self” is due to the body-self neuromatrix. Bodily perceptions (such as pain) which are usually elicited by external inputs are subserved indeed by neural processes in the brain which may act also in absence of any input from the body. Noxious stimuli may therefore trigger the patterns which activate the system but do not produce them.



The major contribution of Melzack body-self neuromatrix model is its ability to account for the various aspects characterizing pain by conceiving of it as the outcome of multiple determinants. In Melzack words,

the neuromatrix theory of pain proposes that the neurosignature for pain experience is determined by the synaptic architecture of the neuromatrix, which is produced by genetic and sensory influences. The neurosignature pattern is also modulated by sensory inputs and by cognitive events such as psychological stress. (Melzack, 1999: S125)

Pathological conditions such as chronic pain syndromes may therefore be re-conceptualized as disruption in a system compounded by several factors whose deep intricacy may account for the failure in treating these conditions with traditional therapeutic means acting on single elements instead of on their connection.

Melzack neuromatrix has proved to be a fruitful model in researches on pain perception and is currently referred to in investigations on pain neural basis. In a recent article, neuroscientists Iannetti and Moraux discuss recent neuroscientific findings on neural basis of pain perception in relation to contemporary developments of Melzack neuromatrix model. By employing neuroimaging techniques such as EEG, fMRI and PET, investigators have seen that the application of noxious stimuli elicits the activation of “an extensive network of brain regions” (Iannetti, Moraux, 2010: 1) which is often identified with a specific “cerebral signature for pain perception.” (Ibidem) This cortical network, which is defined as Pain Matrix, is often seen as concurring with Melzack neuromatrix.

In their article, Iannetti and Moraux recall the formulation of the neuromatrix by Melzack in order to highlight the major difference between the original model and

Pain Matrix one. According to the authors, the main troublesome issue of Pain Matrix is the fact that this network is seen as an actual and localizable specific neural substrate which responds only to nociceptive stimuli. Neural structures constituting Pain Matrix are conceived as a “network of cortical areas ‘mediating pain experience itself.’” (Ploghaus et al., 1999. Quoted in Iannetti, Moraux, 2010: 2) As Iannetti and Moraux emphasize, body-self neuromatrix proposal was made indeed by Melzack “*because* researchers had failed to identify spatially segregated cortical regions specifically devoted to the perception of pain.” (Iannetti, Moraux, 2010: 2) Moreover, conceiving of this neural apparatus as pain specific has led some researchers to conclude that the activation (or the absence of activation) of the Pain Matrix may represent an “objective measure of pain” (Ibidem) to which one may refer to, e.g. in case of medico-legal evidence for compensation requests.<sup>14</sup>

Iannetti and Moraux criticize this interpretation of the Pain Matrix on the basis of contrary evidence. According to the authors, the non-specificity of neuromatrix activity for nociception is indicated by many contrary evidence: i) the impossibility to detect precise cortical areas specific for nociception, ii) the lack of correlation between pain intensity and the magnitude of pain matrix response, iii) the influence of

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<sup>14</sup> In 2011 article, Camporesi et al. discuss the employment of brain imaging techniques in legal contexts, e.g. when people unable to work because of pain ask for disability benefits. The authors remark on the potential fruitfulness of such tool in these situations and indicate also its problematic aspects: the subjectivity of pain may invalidate the “scientificity” of these instruments which is a condition sine qua non for their use in medico-legal context. Moreover, a relevant question is that of the interpretation of these techniques’ findings since the fact that specific brain areas activate when a person is experiencing pain does not imply the converse. See Camporesi et al., 2011

the context in which the nociceptive input is triggered, and iv) the fact that Pain Matrix is activated also by non-nociceptive inputs.

Iannetti and Moraux maintain that the Neuromatrix does not detect nociceptive impulses, but responds to such stimuli because of their *saliency*. The salience of a given stimulus is defined as its “ability to stand out relative to the background” (Itti, Koch, 2001. Quoted in Iannetti and Moraux, 2010: 7); nociceptive stimuli may represent an eminent example of this type of inputs mainly because of their “threatening” the individual. This view is confirmed also by biological theories of pain, seeing of the specificity of pain sensation as grounded on the salience of nociceptive stimuli for the survival of the organism; these stimuli have therefore the capacity to overcome other ones and force the individual to focus on pain in order to produce the appropriate behavioral reaction. By adopting this perspective, neuroimaging findings indicating the existence of a correlation between nociceptive inputs and the activation of the neuromatrix may be shared without the need to postulate a physical specificity of Neuromatrix for pain.

The possibility to localize pain represents a very attractive goal for scientific research. This seems to be due to the attempt to make pain somehow “objective” and, therefore, easily approachable by standardized methods. Nevertheless, such an objective has not been accomplished yet and this makes pain a challenging object for the scientific and, especially, the biomedical knowledge. This issue will be further recalled and discussed as a crucial feature characterizing biomedical approach to pain.

### *1.1.7 Conclusion*

In this section I have focused on the Gate Control theory of pain presented in 1965 by Melzack and Wall; this neurophysiological theory of pain mechanisms represents a fundamental contribution to the change of perspective on pain phenomenon which has led to the acknowledgment of pain as a complex multidimensional entity. I have claimed that two major issues in this regard are the denial of a fixed and invariable relationship between noxious stimulation -and often the tissue damage seen as originating this input- and pain perception, and the acknowledgment of the pivotal role played by psychological factors in pain process.

These issues, as I will argue in chapter II, are crucial also in relation to the constitution of chronic pain as a disease entity. The multifaceted character of pain that Gate Control theory has contributed to acknowledge turns into a troublesome issue when pain becomes chronic and it is difficult to account for it in terms of a single and unequivocal cause. Psychological factors, strongly characterizing every pain condition, will also be interpreted by pain specialists as related to chronic pain in different ways, by producing several interpretations of pain syndromes.

As it has been emphasized, the consequences of this innovative understanding of pain phenomenon are huge for the biomedical approach to pain; nevertheless, if Melzack and Wall theory has had a noteworthy echo in the burgeoning field of pain

medicine, such an influence has not been recorded in biomedicine<sup>15</sup> in general. The ways in which theoretical knowledge of pain emerges and influences clinical practice will be discussed in chapter IV in relation to a particular chronic pain condition, fibromyalgic syndrome.

In this section I have introduced and discussed a change of perspective on pain phenomenon which may be seen as concurring with the shift from specificity model to gate control one. Historian of pain Roselyn Rey has showed how specificity theory -even if strongly challenged by contrary evidence- has remained the dominant theory of pain mechanisms for more than one century. Rey argues that the persistence of this model may have been due to “an accepted *a priori* principle of orderliness holding that every organ is made for one function and one function only.” (Rey, 1995: 136) Moreover, Rey highlights that such a conception may have been retained also because of the “compartmentalized nature of the lines of research” (Ibidem) which gets highly problematic when applied to a complex object such as the nervous system characterized by multiple and reciprocal exchanges between different levels. Rey’s perspective, which stresses the influence of social factors on scientific research of pain, highlights an undeniable feature particularly evident in the clinical handling of pathological pain conditions, i.e. the difficulty to approach pain as a multidimensional object. This aspect will be discussed throughout the course of my work.

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<sup>15</sup> “Biomedicine” is a term coined in the field of medical anthropology to define the specific form of knowledge characterizing Western contemporary medical practice which approaches the human body and its functions on the basis of a biologically-based perspective

Furthermore, by looking at the development of Gate Control theory and in particular in relation to the so-called Pain Matrix, it seems that the acknowledgment of pain as a complex entity is always challenged by what can be called “the temptation of specificity”. In my view, the tendency to locate pain in a specific anatomical substrate is mainly due to the difficulty in approaching a strongly subjective phenomenon such as pain as objectively as possible. The subjectivity of pain is due to the fact that this experience is influenced by several aspects profoundly bounded with the individual’s personal story. Moreover, pain subjectivity is due to the fact that nobody but the sufferer may claim to be in pain and may describe what this experience is like. On the other hand, pain is also a fundamental object of attention for biomedicine, both as a symptom of an underlying disease and as a pathological entity in its own right. In order to be the object of biomedical knowledge, pain has therefore to be somehow quantified and made visible to scientific gaze.

In doing so, what does pain -a subjective and private experience- amount to? How might approach the intricate involvement of several aspects characterizing pain in order to be the object of scientific and in particular of biomedical knowledge?

I argue that the possibility of localizing pain represents a very attractive goal in this regard; in my work I will show how this tendency re-emerges in different ways in the scientific and, especially, in the biomedical approach to pain. In the next section I will discuss this issue by referring to the acknowledgment of pain as a sensory and emotional phenomenon with a focus on the definition of pain given in 1979 by the International Association for the Study of Pain (IASP).

## 1.2 What is pain? IASP's definition of pain

### *1.2.1 Introduction*

In 1979, the IASP proposed an influential definition of pain. IASP's scope was pragmatic, i.e. to provide a definition of the phenomenon which could be shared by pain specialists. This goal seems to have been reached since nowadays IASP's definition is the most quoted in the literature.

As recalled in the previous section, Gate Control theory of pain mechanisms has contributed to the recognition of pain as a complex multidimensional entity by superseding specificity theory which saw pain as a specific sensation due to the stimulation of specific neural structures. This novel conception of pain is grounded on the denial of a fixed and proportional relationship between noxious stimulus and pain perception and on the integration of physiological and psychological features from the beginning of pain processes. This shift of perspective on the phenomenon underlies the definition of pain put forward by the IASP. Here, pain is recognized as a sensory *and* emotional experience whose relationship with the organic tissue damage is so variable that in some cases there may be no actual organic relation at all.

In this section, I will focus on IASP's definition of pain. I will first contextualize it by dwelling on its pragmatic aim, i.e., providing specialists working in the field of a tool share the results of their activities on the basis of a shared definition of the phenomenon. Secondly, I will argue that IASP's definition was mainly meant for clinical purposes. In particular, the most pressing aim of the Association was to

reduce the risk of misdiagnoses of pain when an organic cause was not detectable, by recognizing the reality of all pains.

I will focus then on the definition itself which I will analyze from a philosophical perspective by showing that in this description, which aims at defining pain as an experience, there is a continuous wandering between two different levels of description, a subjective and a “scientific” one. I see this fundamental tension in IASP’s definition as the result of the proponents’ attempt to maintain the multifaceted character of the phenomenon and providing a useful clinical tool to recognize all pains as real. IASP’s definition explicitly accords epistemic authority in pain experience to the sufferer but, if the pain is not accounted for by an organic damage, it is classified as caused by psychopathological causes. My conclusion is therefore that IASP fails in its scope of recognizing the reality of all pains, because in classifying those pains not related to a detectable organic damage as psychogenic, it implies that there is a category of pain which are “less real” than others.

### *1.2.2 Before IASP’s definition: pain as perception and reaction*

The acknowledgment of the constant integrating (and modulating) action played by the CNS promotes also a wider change of perspective on pain phenomenon in itself from a dualistic view to a more complex one: before the introduction of Melzack and Wall’s theory of pain mechanisms, pain was seen indeed as composed by two main aspects or “phases”, pain perception and pain reaction.

In a well-known 1947 paper, *On the nature of pain*, scientists Wolff and Hardy claim that pain may be dissected in two main components: the perception of noxious



stimulus and the reaction to this perception. The perception of pain is a neurophysiological process comparable to other sensory modalities with specific structural and functional properties. The reaction to this perception is composed by different aspects: an emotional response, physical changes, and behavioral reactions in the form of withdrawal, fight or flight. Emotional features are recognized as fundamental aspects of pain, above all in the sufferer's experience; nevertheless, in the authors' perspective, they are just reactions to the perception of the noxious stimulus and are therefore consequential to it.

According to Wolff and Hardy, until the end of XX<sup>th</sup> century, pain was considered to be exclusively a feeling state. Later, with the discovery of the existence of special anatomic equipment and mechanisms for pain, the interest was focused on perceptual aspects of the phenomenon. In the authors' view, pain is both a specific sensation and a feeling. "These two concepts do not oppose each other but only represent different attempts to formulate distinct but crucial aspects of pain experience." (Wolff, Hardy, 1947: 194)

Notwithstanding the recognition of both sensory and emotional aspects of pain, Wolff and Hardy's view of the phenomenon remains anchored to the specificity framework of pain mechanisms in conceiving of pain as quantifiable<sup>16</sup> on the basis of a supposed proportional relationship between stimulus and pain. Psychological (emotional) reaction to pain perception, even if difficult to measure because of the

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<sup>16</sup> A huge part of Wolff and Hardy's work is focused on the evaluation of the pain threshold as the mean to measure pain perception. According to the authors, by quantifying the stimulation needed to reach the lowest pain threshold, it is possible to measure "a clearly definable end point of perception." (Wolff, Hardy, 1947: 170)

subjective variables involved, is nothing but a consequence of the perception of the noxious stimulus.

In the first edition of his textbook on the management of pain, pain medicine's pioneer John J. Bonica (1953) presents a similar description of pain phenomenon: pain involves two main processes, the perception of a noxious stimulus giving rise to the sensation of pain and the reaction to this perception. Compared to Wolff and Hardy, Bonica seems more interested in understanding what the reaction phase entails. This aspect of pain is defined by Bonica as a physiopsychologic process involving the highest cognitive functions of the individual which represents "what the individual feels, thinks and does about the pain he perceives." (Bonica, 1953: 73) The pattern of reaction derives from the meaning of pain sensation to the individual, which, in turn, is related to her past experiences and current attitude toward the sensation such as her mood, emotional and cognitive state.

Bonica's attention to psychological aspects of pain appears to be directly connected to the crucial distinction that he aims to stress between experimental pain, the pain tested in laboratory conditions and clinical pain, i.e. the pain commonly encountered in the clinical practice: experimental pain could hardly reproduce the pain occurring in relation to a disease; the validity of laboratory findings in the clinical domain is therefore questionable.<sup>17</sup> Furthermore, Bonica explicitly claims that even if

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<sup>17</sup> It is worthy to remark that also Melzack and Wall's critique to the specificity model is grounded on the acknowledgment of the difference between the pain studied in the laboratory and the pain experienced by the individual. While the specificity theory could be applied to the first type of pain, aspects such as psychological factors strongly influencing pain experience could not be accounted for by this model

a dualistic perspective on pain (perception and reaction) has proven to be useful in studies such as those on pain threshold, this view has to be abandoned when approaching pain from a clinical standpoint. In the pain encountered in clinical practice, these components are indeed always intertwined: this is why Bonica concludes that “pain cannot be thought of as exclusively either a neurologic or a psychologic condition, but both must be considered and approached clinically as a *gestalt* problem.” (Bonica, 1953: 84)

The stress on the peculiarity of clinical pain is related to Bonica’s aim of proving the need to bring about a brand new approach to pain. The acknowledgment of clinical pain’s complex nature and the consequent need to provide specific treatments for conditions such as chronic pain ground the pain medicine movement leaded by Bonica. The ways in which this operation will be pursued will be presented in chapter III.

Bonica’s conception of clinical pain is grounded on the recognition of the overwhelming gap between this entity and experimental pain: in the pain encountered in the clinical practice, the distinction between pain perception as the direct measurable result of the sensation, and pain reaction as the physiopsychological emotional consequence of this perception, is no more valid; these aspects are deeply intertwined and, as Gate Control theory will show, mutually influent. IASP’s definition will acknowledge this by defining pain as an experience composed by sensory and emotional features.

The influence of Melzack and Wall's theory on IASP's definition appears clear: pain is described as a multidimensional phenomenon, compounded by both physiological as well as psychological aspects. Moreover, IASP indicates that there is a wide gap between nociception and the perception of pain, which is always a psychological state. The definition recognizes the variable link between tissue damage and pain, and dismisses the idea of a one-to-one relationship between stimulus and pain perception. This is also the reason why pain may be perceived without a detectable organic cause.

### *1.2.3 A contextualization of IASP's definition of pain*

According to the IASP, pain is:

*An unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in the terms of such a damage.*

*Note*<sup>18</sup>. The inability to communicate verbally does not negate the possibility that an individual is experiencing pain and is in need of appropriate pain-relieving treatment. Pain is always subjective. Each individual learns the application of the word through experiences related to injuries in early life. Biologists recognize that those stimuli which cause pain are liable to damage tissue. Accordingly, pain is the experience which we associate to actual or potential tissue damage. It is unquestionably a sensation in a part or parts of the body, but it is also always unpleasant and therefore also an emotional experience. Experiences which resemble pain but are not unpleasant, e.g. pricking, should not be called pain. Unpleasant abnormal experiences (dysaesthesiae) may also be pain but are not necessarily so because, subjectively, they may not have the usual sensory qualities of pain.

Many people report pain in the absence of tissue damage or any likely pathophysiological cause; usually this happens for psychological reasons. There is usually

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<sup>18</sup> In IASP's Taxonomy, each term is accompanied by a note on usage which is usually considered as an integral part of the definition

no way to distinguish their experience from that due to tissue damage if we take the subjective report. If they regard their experience as pain and if they report it in the same ways as pain caused by tissue damage, it should be accepted as pain. This definition avoids tying pain to the stimulus. Activity induced in the nociceptor and nociceptive pathways by a noxious stimulus is not pain, which is always a psychological state, even though we may well appreciate that pain most often has a proximate physical cause.<sup>19</sup>

Writing in 1979, John J. Bonica, who is also one of the main promoters of the constitution of the IASP, indicated the formulation of a taxonomy of pain phenomena and the development and widespread adoption of terms' definition as two among the most important scopes of the association. The purpose of this work was explicitly pragmatic, i.e. providing professionals working in the field of pain of conceptual tools to collaborate, share the results of their work and communicate with each other. In order to constitute this new branch of medicine, one of the first step to take was to make different specialists working on pain sharing their views and possibly collaborating between them; the availability of a common set of terms and related shared definition was necessary for this goal. Moreover, as Baszanger highlights, the definition of pain as an experience -and not as a sensation- which places the individual in the foreground, indicated also the possibility to approach pain from different perspectives, either physiological and psychological. In this way, IASP's definition of pain legitimates different therapeutic approaches to painful conditions,

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<sup>19</sup> IASP, 2010. Quoted in Wright, 2011. From the first formulation of the definition (1979) some changes have been made. The most relevant one is the addition of the first sentence in the Note related to the communicability of pain

representing the different perspectives of pain medicine's movement united in the aim of fighting pain.

As Wright (2011) notices, when pain definition and taxonomy were first put forward (in 1979), Bonica and the IASP's Subcommittee responsible for the taxonomy indicated that this tool was addressed to all the professionals working in the field of pain and that it was meant to represent a "minimum standard vocabulary" (IASP, 1979: 249. Quoted in Wright, 2011). Notwithstanding the difficulties of such a wide enterprise, Bonica claimed that the effort was necessary and worthwhile; moreover, by considering the definitions and the taxonomy perfectible, he explicitly invited pain experts to test their efficacy, and possibly discuss them on the basis of an actual employment in their activity.

In the later edition of *Pain Terms* (1986), the Subcommittee on Taxonomy narrowed down the aim of the work by claiming that they "have been developed for use in clinical practice rather than for experimental work, physiology or anatomical purposes" (IASP, 1986: S216). The reason for this restriction of the definitions' aim appears more clear when contextualizing the two claims: in 1979, the International Association for the Study of Pain was new-born (IASP was officially founded in 1974). In 1975, during the first worldwide Congress of the Association, the Committee working on the Taxonomy of pain terms is created and in 1979 the first list of terms' definitions and the taxonomy is published. In this perspective, it may be argued that while at an early stage of the constitution of pain medicine's movement the main aim was to facilitate the participation of different subjects by involving the

biggest number of potentially interested people, later, with the reinforcement of the Association, the proponents restricted the applicability of pain's terms and classification to the clinical practice, therefore to a narrower group of pain specialists, those dealing with pain patients.

The definition of pain and the related Note appear to be directly aimed at a precise clinical issue, i.e. that of avoiding the risk of a misdiagnosis of those pains reported by sufferers but not accounted for by a detectable organic damage. In other words, the main aim of IASP's definition was to force physicians to recognize the reality of all pains. The relevance of this issue emerged clearly in a 1968 paper on the psychology of pain by psychiatrist and pain specialist Harold Merskey who presented what seems to be the draft of IASP's definition. Merskey criticizes physicians' common habit of seeing pain as "evidence of a physical disease" (Merskey, 1968: 297), which may entail neglecting the reality of those pains reported by patients but not related to an organic damage. The author challenges this view by arguing that pain is always a psychological state and that it is also often caused by psychological factors. Moreover, Merskey claims, the common view of pain as resulting from a noxious stimulation of physical substrates is strongly challenged by neurophysiological findings such as those brought about by Melzack and Wall's theory. In the light of this evidence, Merskey concludes that the absence of a physical damage does not entail the absence of pain; a viable definition of pain describes it as "an unpleasant experience which we primarily associate with tissue damage or describe in terms of such damage, or both." (Ibidem) According to the

author, in this way the relationship between pain experience and the damage is preserved, but no assumption is made in relation to the cause of pain.

As I will later argue in relation to IASP's definition of pain, the attempt to overcome the conception of "real pain = organic pain" on the basis of the existence of "psychogenic" pains, is tricky: this argument may lead to conclude that those experiences described by the sufferers as pains which do not have a detectable organic cause, are always caused by psychological factors. The relevance of such a perspective is huge in relation to conditions such as chronic pain, where the persistence of pain is often not accountable for by an underlying damage.

#### *1.2.4 Fundamental tension(s) in IASP definition of pain*

Philosophers Aydede and Güzeldere argue that in IASP's definition, and more generally, in scientific studies on pain, there is "a fundamental tension between pain as subjectively understood versus pain as objectively characterized".(Aydede, Güzeldere, 2000: S266) Even if I agree with their analyses, I don't see this tension -and the stress on subjective experience- in IASP's definition as due only to the "pain's complex phenomenology involving an affective/motivational dimension". (Aydede, Güzeldere, 2000: S265) In my view, the mentioned tension is primarily due to the purpose of the definition's proponents, i.e. providing a description of pain which could be useful in a clinical perspective. This is the reason why IASP stresses the subjective experience of pain (in which pain is always pain, no matter whether a tissue damage is present or not). Nevertheless, the focus on subjective features is more apparent than actual in IASP's definition, which refers instead mainly to an



organic conception of the phenomenon.

### *Pain as experience*

The most striking character of IASP's definition is its description of pain as an experience, by stressing therefore the sufferer's standpoint. As already anticipated, the choice to define pain from the individual's point of view seems to be aimed at recognizing the reality of all pains: if the sufferer claims to be in pain, the physician has to accept it, even when there is no organic damage. Defining pain as an experience entails also a major stress on the subjectivity of the phenomenon: pain is an experience deeply rooted in the sufferer's individuality. As Gate Control theory has showed, from a neurophysiological viewpoint pain perception is highly influenced by the individual's past experiences, present attitude toward pain expectations on the future. The acknowledgment of the subjective dimension of pain goes together also with the recognition that the perceived magnitude of pain can be highly variable, depending on the individual and the situation in which pain is experienced. This has an important consequence on the clinical practice: physicians may assess the intensity, frequency and quality<sup>20</sup> of pain only through the sufferer's own report. The subjectivity of pain, i.e. its being inner and private, has also a relevant impact on the epistemic nature of pain: nobody but the sufferer who is actually experiencing it may

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<sup>20</sup> As I will discuss in the last chapter of the dissertation based on the observation of rheumatological clinical encounters, the assessment of the type of pain experienced by the sufferer is noteworthy and fundamental to the clinician's work, in particular in relation to the diagnosis, e.g. inflammatory pain differs from the pain related to degenerative diseases

have access to her own pain. IASP explicitly accords to the sufferer reportorial authority in pain experience.

*Pain as a sensory and emotional experience*

IASP claims that pain is experienced by the sufferer as something sensory and emotional. Pain is experienced as a sensation in a precise area of the body. This appears to be true, even in those cases in which pain is widespread or changeable in location, or the location of pain does not coincide with the damage site. Furthermore, pain has an emotional side which is due to the fact that it is unpleasant to the sufferer.

The way in which IASP puts the sentence (*pain is an unpleasant sensory and emotional experience*) seems to suggest that the sufferer may distinguish in her own experience sensory and emotional aspects of pain: pain is a sensation *in* the body which has an unpleasant emotional connotation. IASP appears here to attempt appreciating the individual's perspective on pain, but this, I argue, is not the point that IASP aims at making. So what is the scope of defining pain as *a sensory and emotional experience*? As a matter of fact, this definition does not either seem helpful for another person to get an access to another individual's pain, e.g. a clinician; furthermore, what does the adjective "emotional" refer to, if IASP already states that pain is always unpleasant? In the Note, IASP claims that pain *is also always unpleasant and therefore also an emotional experience*: if the emotional aspect of pain experience is due to its unpleasantness, isn't the first part of the sentence redundant? I suggest that here IASP's definition refers not to the sufferer's

experience, but to the scientific description of pain, which, as Gate Control theory indicates, is a complex phenomenon involving sensory and emotional aspects, and not, as the previous specificity framework postulated, a sensation. As I've anticipated, in IASP's claim the definition of the phenomenon from the individual's perspective is accompanied by a scientific perspective on pain concerning its aetiology. Let us give a noteworthy example the way in which IASP employs the terms "emotional" and "psychological": while the former seems to characterize the subjective experience of pain, i.e. an emphasis on the individual variations in pain perception, when defining pain and, above all, the potential cause of pain, this term is substituted by "psychological" (*psychological reasons, pain (...) is always a psychological state*).

The conjunction *and* which keeps together sensory and emotional aspects of pain is, in my view, emblematic of the difficulty to tackle pain as an experience, i.e., as a unitary phenomenon: the sensory aspect of pain correlates this psychological state to one or more specific body parts, while the emotional aspect -derived from its unpleasantness- has to do with the psychological status of pain perception. The IASP definition continually wavers between these two aspects of pain: on the one hand, sensory pain features correlate it to other sensory modalities that locate the sensation and tend to relate pain to an organic substrate, with respect to its aetiology (pain is associated to actual or potential tissue damage or described as the pain caused by it) and its perception (localization). On the other hand, there is an on-going

attempt to encompass pain as a psychological state, and therefore as a strictly subjective phenomenon.

*Associated to an actual or potential tissue damage or described in the terms of such a damage*

The second part of IASP's definition claims that pain experience is always associated to a tissue damage which may be actual, potential or described in these terms. But what kind of relationship underlies this association (a very broad term) and, above all, who is the subject of this association?<sup>21</sup>

From a first reading of the sentence, the association of pain with the tissue damage seems to be made by the sufferer: again, IASP appears to describe the experience from the first person's point of view. If one goes further to the Note, this association is justified also on the basis of a biological evidence (*biologists recognize that those stimuli which cause pain are liable to damage tissue*); in this sense, the relationship of pain and tissue damage refers to the evolutionary role of pain for the individual' survival. As Wright remarks, this relation concerns all pains and may therefore represent an universal characterization of the phenomenon.

The nature of the association of pain experience to the tissue damage is accountable either in a scientific perspective as in the common experience (*Each*

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<sup>21</sup> Price (1999) questions the clarity of this sentence by claiming that it is not clear from whose point of view such an association exists: if the subject of this sentence is interpreted to be an external observer, it may be concluded that if he or she does not notices the link between the pain reported by the sufferer and the tissue damage, the experience cannot be recognized as pain

*individual learns the application of the word through experiences related to injuries in early life).*

The relationship between pain and tissue damage is not always actual, but may also be potential or described like that. The adjective “potential” can be interpreted as related to the definition of noxious stimulus as “an actually or potentially tissue-damaging event transduced and encoded by nociceptors”. (Loeser & Treede, 2008: 475. Quoted in Wright, 2011) The definition of noxious stimulus is tautological: a stimulus is noxious when it has a potential or actual tissue-damaging character and therefore, it is capable to elicit pain sensation. The discussion of what characterizes a stimulus as nociceptive is beyond the scope of my work; nevertheless, I shall tentatively reply to a more general question, i.e. is there anything common to all pains which may account for some peculiar aspects of the phenomenon? In this regard, Iannetti and Moraux’ suggestion, that nociceptive stimuli have a high saliency because of their threatening character (See 1.1.6 Gate Control theory today), seems to be fruitful also in a wider perspective: the opposing character of pain sensation, i.e. the fact that pain “makes you want to run away from it” may be indicated as a feature common to all the pains and shareable both in biological perspective and in everyone’s experience.

Coming back to IASP’s definition, the claim indicates that pain may also be associated to something described in terms of tissue damage. This specification is directly aimed at pointing out that, even if there is no detectable tissue damage, if the sufferer reports to feel pain in the same way as when the pain related to a detectable

tissue damage, then her pain has to be recognized as real. This claim is explicitly made in the Note in relation to those cases in which patients report to be in pain even without a detectable pathophysiological process. Usually, IASP argues, *this happens for psychological reasons*. From my perspective, this is the most problematic part of IASP's definition: here, the attempt to encompass all that the individual experience can define as pain (whether the cause is tissue damage or not), is challenged by a clear-cut categorization of it in a dualistic framework. Even if it is stated that the sufferer should be given epistemic authority in pain experience (Aydede, Güzeldere, 2000: S268), as a matter of fact this authority is restricted to the presence of pain, i.e. if the sufferer claims to be in pain, the physician has to believe that this assertion is true; the reason why the individual is in pain is already decided: if there is no identifiable tissue damage and the person claims to be in pain, the cause has to be psychological. IASP definition acknowledges the reality of all painful experiences, but at the same time fits them into an aetiology-grounded model which dichotomizes mind and body relations, classifying pains without organic detectable cause as "psychogenic". The troublesome issues affecting this categorization of pain will be discussed in the next chapter.

#### *1.2.5 Epistemological issues in IASP's definition of pain*

In their 2000 paper, philosophers Aydede and Güzeldere discuss the peculiar status of scientific research on pain. The authors pinpoint a fundamental tension in pain research -and in IASP's definition of the phenomenon- between "what can be quantified as the 'objective' measure of pain as characterized in terms of tissue

damage and the 'subjective' criterion of when to categorize a given experience as pain." (Aydede, Güzeldere, 2000: S267) Specifically, the authors are concerned with the target of causal explanation of pain which in IASP's definition is doublefold, i.e. a subjective one grounded on the sufferer's reportorial authority and an objective one, based instead on the presence or absence of a detectable tissue damage. Aydede and Güzeldere argue that, following IASP's definition, "the scientists seem to take themselves to be studying or explaining the objectively observable *causes* of a subjective phenomenon (the introspectively accessible pain experience) but not the pain understood as an objective physical state." (Ibidem) In this way, IASP's definition indicates that scientific (neurophysiological) explanations of pain phenomenon are secondary to the subjective explanandum. However, as the authors highlight, IASP's definition does not go that far and leaves this question open. Secondly, in a neurophysiological perspective, it is obvious that, if pain experiences coincides with brain states, when these states are recognized, this knowledge has the same degree of authority of the subjective one. Moreover, Aydede and Güzeldere conclude, instead of seeing the issue of pain subjectivity as a problematic issue for scientific studies on pain, this may instead represent a resource for neuroscientists by implementing the neurophysiological findings with information available only through the subjective introspection. (See Aydede, Güzeldere, 2001: S271)

While Aydede and Güzeldere are mainly concerned with the implications of the IASP's definition with neurophysiological studies on pain, my aim is to understand what this definition may entail in a clinical perspective. As I have already indicated,

the tension underlying IASP's definition between subjective and objective explanation of pain phenomenon may have noteworthy consequences on clinical practice: following IASP's definition, the clinician is supposed to recognize the reality of all the pains reported by her patients. At the same, IASP claims also that, if the physician cannot detect an organic cause accounting for the patient's pain, she has to conclude that the patient's pain is caused by psychopathological disturbances. By contextualizing this claim in an actual clinical setting, if a patient claims to be in pain but the physician cannot detect any signal of organic injury, the patient has to be directly referred to a psychologist or a psychiatrist. As the findings of my observation of clinical interactions will show, such a clear-cut approach to the sufferers' pain is rarely pursued in clinical practice where the situation appears to be much more complicated. Nevertheless, it is arguable that the tension between pain as subjectively understood (patient's perspective) and pain as objectively characterized (scientific perspective) may turn into a conflict between two different descriptions of the phenomenon which as, in IASP's definition, generate a clash. The ways in which this conflict takes form in clinical practice will be analyzed in the fourth chapter.

### *1.2.6 Conclusion*

Unlike other authors' (See e.g., Hardcastle, 1999 and Wright, 2001), my analysis of IASP's definition was not aimed at investigating whether it could represent universally shareable definition of the phenomenon. In my perspective, this goal cannot be achieved because the intrinsic complexity of pain does not allow a univocal definition of the phenomenon. However, I believe that it is possible -and



necessary- to ask whether IASP has provided a useful tool to approach a specific entity, that is, clinical pain. As I have already anticipated, even if I see IASP's definition as a remarkable attempt to tackle pain phenomenon in its several aspects, I argue that this attempt has failed. The main failure of IASP's definition is its aiming at recognizing the reality of all pains and, at the same time, its invalidating this effort by classifying those pains without an organic detectable cause as psychogenic. As I will show in the next chapter, psychogenic pain is an umbrella term which is still employed nowadays to define those pains which are supposed to be caused by psychopathological causes. This blurred classification of pain is usually grounded on the exclusion of a detectable organic cause for pain, and not on positive criteria. The employment of such a questionable label for pain does not seem to be helpful since it does not define a precise clinical entity and this is why its inclusion in IASP's definition is not acceptable either.

## Chapter 2

### PATHOLOGICAL PAIN: PAIN AS A MENTAL DISORDER

#### *2.1. A history of psychogenic pain*

##### *2.1.1 Introduction*

Tracing the entire history of the concept of psychogenic pain would be a huge task and an unnecessary endeavor for the purposes of the present work. This is mainly because “psychogenic pain” can be conceived of as an umbrella term that may group a variety of different concepts and painful conditions.

In this section, I will present a brief history of “psychogenic pain” by recalling the main interpretations of this notion -and of the supposed psychological mechanisms causing pain- in the psychiatry debate from the second half of the XX<sup>th</sup> century; simultaneously, I will recall the classifications of this entity proposed by the American Psychiatrist Association (APA) in the different editions of the Diagnostic and Statistic Manual of Mental Disorders (DSM). My aim is to analyze the relationships between the changes in the APA's classifications of this entity and the relevant psychological theories of “psychogenic pain”. In particular, the history of the nosologic classifications of this entity is related to the history of the diagnostic category of “hysteria” and to its refashioning in the DSM.

This analysis will also provide historical, conceptual and philosophical analyses of the issues involved in the definition of pain as a psychopathological entity, specifically

of pain as a somatic symptom caused by psychological issues, which will ground the discussion presented in the III chapter on the framing of chronic pain as a disease.

Etimologically, the term “psychogenic” derives from the Latin words *psyche* and *genus*, recalling therefore something originated in the mind. In a broad sense, “psychogenic pain” refers to all those pains caused (or supposed to be caused) by psychological factors.

In the same paper in which the draft proposal of IASP’s definition of pain is presented, psychiatrist Harold Merskey claims that in the mid-Sixties three main psychological mechanisms causing pain were recognized: the first one is that of hallucinatory pain, which can be associated with schizophrenia or with endogenous depression; the second operates when pain is caused by muscular tension due to a psychological state such as anxiety or as migraine pain; the third mechanism is that of conversion hysteria. While hallucinatory pain in schizophrenia is rare, Merskey points out that in other psychiatric conditions such as neurotic depression, anxiety and hysteria, pain is a frequent phenomenon. As hallucinatory pain and pain caused by muscular tension are less important for the issues that this thesis addresses, I will especially focus on the evolution of the conception of pain as a conversion symptom.

### *2.1.2 Pain as a conversion symptom*

The interpretation of pain as a conversion symptom has become well-known with Breuer and Freud's *Studies on hysteria*, in which pain is a prominent symptom in the cases considered (Breuer, Freud: 1895). However, the different interpretation of the aetiology of these pains given by the authors are noteworthy. Freud conceived of

them as the result of a “pure” psychological process, a defensive mechanism of the ego against a traumatic (painful) and therefore repressed memory through the conversion in a somatic symptom such as pain. Breuer, instead, according to his conception of ideodynamism<sup>22</sup>, believed that many hysterical pains were not solely caused by “ideas” but, following Charcot, that “the overexcited, diseased nerves of the hysteric were central to the phenomenon, acting to enliven traumatic reminiscence.” (Hodgkiss, 1995: 198)

In the second half of the XX<sup>th</sup> century, hysteria “disappears” as a valid diagnosis, like the idea of pain without organic lesion as a typical hysterical symptom; as historian Micale argues, what actually disappeared was the term hysteria and its derivatives as hysterical pain, while the nosologic content remained. In his crucial work on the history of hysteria (1995), Micale argues that the “vanishing” of hysteria is due to a process of “clinical redefinition and reclassification” (Micale, 1995: 292) of the disease, grounded on a “dismemberment” of the old category and a subsequent redistribution of hysterical main features in other nosologic classifications<sup>23</sup>. In the first edition of the DSM (1952), the old “conversion hysteria” figures in the category of “psychoneurotic disorders” -whose main pathological feature is anxiety- as *Conversion reaction*; this condition is diagnosed when it is recognized that the

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<sup>22</sup>“I subscribe to the opinion that 'ideas', mnemonic images pure and simple, without any excitation of the perceptual apparatus, never, even at their greatest vividness and intensity, attain the character of objective existence which is the mark of hallucinations.” (Breuer, Freud, 1895: 188)

<sup>23</sup> Micale argues that this operation is the consequence of a de-Freudianization of psychiatric science which has tried to turn diagnosis deeply bounded to psychoanalyses’ framework into more biologically-grounded categories

impulse generating anxiety is not felt consciously by the individual but it is converted into a functional (or more than one) symptom. Pain is not included in the list of these symptoms. Some painful conditions with psychological aetiology are however already present in the first DSM edition elsewhere: in DSM-I they are classified as *Psychophysiologic musculoskeletal reactions* (002-580) including “musculoskeletal disorders such as 'psychogenic rheumatism', backache, muscle cramps, myalgias in which psychological factors play a causative role.” (APA, 1952: 30) It is also made explicit that the “differentiation from conversion reactions is of prime importance and at times is extremely difficult.” (Ibidem) In the DSM-II (1968) the changes from the first edition are minor: this category becomes *Psychophysiologic musculoskeletal disorder* (305.1), the description remains the same and it is restated that “differentiation from hysterical neurosis is of prime importance and at times extremely difficult.” (APA, 1968: 46) The difficulty in making such a distinction seems to be related to the differential diagnosis, in which symptoms probably often overlap. An outstanding difference between these categories -*Conversion reaction* and *Psychophysiologic musculoskeletal disorders*- is indicated at the aetiological level: while in *Conversion reaction*, the conversion mechanism is conceived of as purely psychological, in *Psychophysiologic musculoskeletal disorders* the disorders are seen as due to “a chronic or exaggerated state of the normal physiological expression of emotion”<sup>24</sup> indicating a mixed psychophysiological aetiology of the

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<sup>24</sup> APA, 1952: 29

condition in which the anxiety triggers a pathological reaction that instead of being converted, is expressed into muscular tension.

It may be worth highlighting that in the DSM description of the “psychoneurotic disorders” category, anxiety is defined as “a danger signal (...) produced by a threat from within the personality with or without stimulation from such external situations as (...) threat of injury.” (APA, 1952: 31-32) Even though pain is not mentioned as a conversion symptom in this categorization, the relationship between anxiety and pain is been pointed out in the psychoanalytical thought and by Freud himself<sup>25</sup>, and it has been explicitly theorized by authors such as Thomas Szasz. In Szasz's perspective, the split between anxiety and pain is typical of Western culture; this has led to psychiatrists and psychoanalysts dealing mainly with anxiety and related conditions, but only with a particular type of pain -psychogenic pain- while “organic pain” is seen instead as a physicians' concern. In his work on pain and pleasure, Szasz argues that, in general, pain can be seen as the consequence of a threat to the integrity of the body. In a Freudian psychoanalytical perspective, the body is regarded by the self as an object of concern. In this sense, Szasz argues that “when we consider pain in terms of the relationship of the body to the ego, the distinction between 'organic' and 'psychogenic' disappears” (Szasz, 1988: 70), because the perceived threat may be psychological (internal) rather than physical (external). In his perspective, the separation between organic and psychogenic pain is related to a validation issue:

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<sup>25</sup> Freud, 1926. In *Inhibition, Symptom and Anguish*, Freud dedicates many reflections to the role played by pain in psychopathology, particularly to its relationship with anxiety

when an external observer judges the dangerous stimulus appropriate at evoking pain, then the experience is “objective” and the pain is organic; conversely, when the observer does not recognize an appropriate source of danger, pain is seen as psychogenic.

### *2.1.3 Pain as a communication tool*

In Freud's conception of hysterical pain, the supposed mechanism underlying pain is that of conversion, a defensive mechanism of the ego against a traumatic reminiscence<sup>26</sup>; referring to the treatment of Elisabeth von R.<sup>27</sup>, Freud describes this process as based on the fact that “in place of the mental [*seelische*] pains which she avoided, physical [*körperlich*] pains made their appearance”<sup>28</sup>. As remarked by Hodgkiss, Freud believed that “many lesionless pains were symptoms of psychic origin, caused by repressed reminiscences that could be abolished by cathartic speech.” (Hodgkiss, 2000: 164)

As Professor David-Ménard highlights, in Freud's analyses the pain of hysterical women is opposed to the ordinary organic pain because in the case of hysterical pain the body seems to be a pretext for a language lacking in cognitive aims. (David-Ménard, 1989: 18-19) According to David-Ménard, hysterical pain is the material component of a language strongly related to a physiological reality, which supports

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<sup>26</sup> In Freud's conception, the intolerable memory is mainly conceived of as an incompatible sexual idea; this interpretation of the source of hysterical repression will lead also to the distancing of Freud and Breuer

<sup>27</sup> In the cases collected in *Studies on Hysteria*, Fraulein Elisabeth von R., Frau Cäcilie and Emmy von N. suffered from “hysterical pains”

<sup>28</sup> Breuer, Freud, 1895. Quoted in David-Ménard, 1989: 10

“another type of reality whose ambiguous status (...) Freud indicates by speaking of hysterogenic zones.” (David-Ménard, 1989: 19) In the case of Fräulein von R., this polysemy of pain emerges clearly: “if one pressed or pinched the hyperalgesic skin and muscles of her legs, her face assumed a peculiar expression, which was one of pleasure rather than pain.” (Freud, 1956: 37) Here, Freud draws attention to the patient's reaction to stimulation of the painful areas, which, instead of suffering, is of relief; in this way, Freud points out the peculiar status of the pain as hysterical symptom, that of being a way in which the patient's psychic conflict -unexpressed by means of words- is communicated through the somatic painful symptom and, in this way, the patient' suffering is somehow alleviated.

In his work on pain pleasure (1957), the psychiatrist Thomas Szasz specifically focuses on “psychogenic pain” by arguing for the communicative role of pain in the patient-physician relationship. In his perspective, pain represents a communication tool under several respects: first of all, pain is a message sent from the body to the ego, indicating a potential danger and asking therefore for protection. At a second level of symbolization, pain comes to be in the childhood process of development a request for help (to the people supposed to relieve the child's painful state), that is maintained in adulthood with the same meaning. Szasz defines the first level as the *medical meaning* of pain and the second one the *communicative meaning* of pain. On a third level, this request for help conveyed by pain may be addressed to a particular person, “from whom assistance may be expected” (Szasz, 1975: 89). By applying this scenario of pain's different meanings to the clinical field, Szasz claims



that the patient's pain "arises out of a need which may be that of a bodily disorder, or (...) another need. The experience and expression of pain is an attempt to satisfy this need." (Szasz, 1975: 90) In Szasz's perspective, this conception may also explain the aggressive approach of some patients suffering from chronic pain to the physician: according to the author, the patient's expectation -that the doctor cures the pain- hides a broader one, that of having an existential suffering alleviated, hope that obviously keeps on being frustrated.

In a 1975 comment to his 1957 work, the author recalls the case of Fräulein Elisabeth von R. and comments on Freud's analyses. Szasz argues that, as in this case, for many people suffering may become a career because "playing the sick role may (...) be the most gratifying pursuit open to them." (Szasz, 1975: xxv) This peculiar individual, called by Szasz *homme douloureux*, is described as "a person whose humanity is intimately related to, or is wholly dependent upon, his being in pain and suffering." (Szasz, 1975: xxxix) Moreover, Szasz presents a striking critique to the "use" of pain -particularly evident in those cases in which pain persists without a discernable organic aetiology- in the patient-physician relationship. The psychiatrist argues that this sort of relation is grounded on a mutual deception: the patient deceives the doctor by asserting that she is suffering of a bodily illness, while the physician deceives the patient by claiming that he believes that the patient has an organic disease; here, the pain authenticates the patient's illness as a physical one and hence allows this individual to play the sick role and the physician to maintain the medical one. In Szasz' view, this arguable approach to pain by both physicians and

psychiatrists is due to the idea that if a person complains of pain, she has to be sick, either physically or mentally. Szasz sees this situation as a denial of the essence of patient's pain, that is the fact that the pain "creates meaning for his life and power to control his human environment." (Szasz, 1975: xlix) The psychotherapist, instead, should approach this individual "by treating the client as a person responsible for his life rather than a patient not responsible for his lesion, by treating pain as an idiom, rather than as an illness" (Szasz, 1975: li). From the author's perspective, these individuals' pain is therefore a language to tell about an existence dominated by pain. In acknowledging these pains as organic, both the patient and the physician try to adhere to the traditional view of pain as a symptom of disease; Szasz' contention is that, in this way, the message inherent to patient's pain is denied by both sides.

#### *2.1.4 Psychiatry and pain in the Sixties*

The first large review of psychiatric patients with pain is reported by psychiatrist Allan Walters in his 1961 study. Walters claims that psychological factors may cause pain in three ways: psychogenic magnification of physical pain, the fact that "our physical pains all grow stronger when they are on our minds" (Walters, 1961: 2), psychogenic muscular pain, and psychogenic regional pain, a label that he suggests as a substitute for hysterical pain. The latter category refers to regionally located "pains patients feel in their bodies, and for which the clinician finds no physical lesion or peripheral cause." (Walters, 1961: 1) Walters rejects the label "hysterical pain" for these patients because he believes hysterical processes cannot account for the majority of these pains, which instead may be associated with psychosis, other type

of neuroses and situational states. This leads Walters to conclude that, generally, pain is not an indicator of a peculiar psychological disorder. What these individuals actually share is a similar story before pain onset: the majority of them, at a certain point, find themselves unable to cope with a difficult life condition; this is when they start declining and, when the situation becomes untenable, “some stimulus arises which carries from the past or the present a *noxious*<sup>29</sup> significance for the patient” (Walters, 1961: 14) that “seems to trigger a pain mechanism and the patient finds himself with a region of his body in pain and with that region acting as if it were injured.”

These findings lead Walters to the conclusion that this syndrome is a “behavioural expression of a personal state of danger or injury” (Walters, 1961: 17) in which patients' pain is an hallucination (a sensory perception without peripheral stimulation) triggered by a mental activity. However, Walters concludes that if this phenomenon is related as it seems to a process of symbolization, the explanation of this mechanism has to be found in the nervous system, and more precisely, in the brain.

In the Sixties, psychogenic pain is at the core of the investigations of a group of British psychiatrists working at the University of Sheffield coordinated by Erwin Stengel, Head of the Psychiatry Department at that time. Three junior researchers of

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<sup>29</sup> Italics added

this team later become re-known experts in the field of psychological pain<sup>30</sup>: Harold Merskey, Izzy Pilowsky and Sir Michael Bond. (See Tyrer, 2006: 91)

In 1965, the British Journal of Psychiatry reports Erwin Stengel's Maudsley Lecture before the Royal Medico-Psychological Association on the relation between psychiatrists and pain. Here, Stengel complains that psychiatry seems to be very little concerned with the issue of pain and its treatment, and provocatively argues that this may be one of the reasons “why the psychiatrist has not enjoyed the same prestige as other doctors.” (Stengel, 1965: 795) Stengel remarks that the belief that pain is mainly due to physical causes has favored researches on physiological aspects of pain. Despite this, psychogenic pain -even if vaguely defined- is often presented in clinical settings even though physicians usually neglect it: it is psychiatrists' task to be concerned with it. Recalling the most important work done in the field, Stengel concludes the lecture by claiming that, against the general belief, pain is a common psychiatric symptom and a “psychiatric approach is indispensable in the study and treatment of pain, whatever its origin (...) because pain is essentially a mental state.” (Stengel, 1965: 802)

In the same period, in the US psychiatrist George Engel presents his work on psychogenic pain. Engel (1951, 1959) describes twenty patients with facial pain, regarding them as suffering from an hysterical conversion symptom. Engel emphasizes these patients' common “masochistic” behavior, which puts them often in

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<sup>30</sup> Harold Merskey and Izzy Pilowsky will also have a prominent role in the debate on psychological painful conditions in pain medicine

unhappy situations, and their peculiar relation to pain which makes them feel it with greater intensity or frequency than usual. In 1959, Engel proposes the notion of the “pain-prone patient”, referring to a specific personality who tends to suffer pain without an organic aetiology. In Engel's view, the experience of pain in these patients may be initially related to a peripheral change, but then pain becomes a psychological phenomenon which in the “pain-prone patient” does not require the presence of peripheral stimulation anymore.

The psychic experience of pain develops from what is originally a reflex protective system of the organism to preserve it from external injuries; when the psychic organization for pain has evolved, external stimulations triggering pain are no longer required so that pain may occur (and be felt in the body) even without peripheral stimulation and becomes indistinguishable from the experience triggered by such external input. Pain is an important aspect of the psychic evolution of the individual, and in the child's development pain and its relief are pivotal in the constitution of interpersonal relations and in the formation of concepts such as good and bad, reward and punishment, success and failure.

On the basis of clinical studies on pain patients, Engel concludes that there is a category of individuals who are more prone than others to use pain as a psychic regulator, that becomes therefore an instrument employed by the patients in order to deal with situations potentially dangerous for the self.<sup>31</sup>

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<sup>31</sup> Usually this attitude derives from a pattern established in childhood. “These patients usually were reared in a family situation in which aggression and pain figured prominently. Either the patients experienced frequent

Engel draws a profile of these individuals by indicating some common features in their life' stories such as: a prominence of conscious or unconscious guilt atoned through pain, a masochistic behavior that puts them frequently in painful situations (such as multiple surgical interventions and treatments), a frequent employment of pain to handle situations of threatened or actual relationships' loss, the development of pain to counterbalance an unexpressed aggressiveness, a tendency toward sado-masochistic sexual development, a location of pain related to unconscious identification with a love object.

According to the author, these individuals' relation with pain is due to "a long term background of guilt and/or guilt-provoking situation precipitating pain. Even though they complain of pain, for them the pain is almost a comfort or an old friend (...) it is an adjustment, a way of adaptation, acquired through psychic experience." (Engel, 1959. Quoted in Adler et al., 1989) In Engel's theory, pain is seen as an instrument unconsciously used by the patient to attenuate "the guilt and shame of the depression" (Blumer, Heilbronn, 1982: 384), and not a symptom of depression itself.

The idea of a pain-proneness will be later drawn on by Blumer and Heilbronn (1982), who will see, instead, in the chronic pain without organic lesion a masked depression. The relation between chronic pain and depression is still currently debated. This issue will be tackled in the next section on chronic pain as a pivotal topic in the definition of chronic pain as a disease in biomedicine.

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abuse, thus learning that painful attention meant that the patient cared (as other children learn to value affection), or else distant parents showed concern only when these patients were sick or hurt. In any event, a pattern of suffering was usually established in childhood." (Sternbach, 1974: 25-26)

### *2.1.5 Pain and somatization*

In a 2004 review of the literature on psychogenic pain, Merskey claims that the nineteenth century solution to the problem of “pain without lesion” was a diagnosis of hysteria; actually, the author argues, it is clinically difficult to demonstrate that pain is an hysterical symptom, since it could be proved only on the basis of the identification of the emotional issue that is supposed to cause pain which, when alleviated, entails also the ceasing of pain. Moreover, the patient should also agree with this explanation of her pain, i.e. that its presence was aimed at “solving a particular problem.” (Merskey, 1004: 68) According to the author, in the DSM-III the refashioning of hysteria’s diagnosis was supplied by the category of Somatoform Disorders, in which conditions characterized by hysterical symptoms, but not pain, were classified in *Conversion Disorder* category<sup>32</sup>, while those presented only with pain symptom were diagnosed as having *Psychogenic Pain Disorder*.

The clinical description of DSM-III *Psychogenic Pain Disorder* indicates that, in order to receive this diagnosis, the patient has to have severe and prolonged pain without organic pathology or pathophysiological mechanisms accounting for pain, and the patient's complaint has to be grossly in excess in relation to the physical findings (the presence of an organic pathology is accepted). Evidence that psychological factors play a role in the production of pain is: a temporal relationship between pain onset and environmental factors producing psychological conflict; the

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<sup>32</sup> Micale (1995) indicates a wider redistribution of hysterical features in the DSM-III categories: *Factitious illness behaviour, Dissociative Disorder- conversion type, Histrionic Personality Disorder, Undifferentiated Somatoform Disorder* and, finally, *Psychogenic Pain Disorder*

fact that pain appears to enable the patient to avoid activities noxious to her, and the fact that the presence of pain somehow enables the patient to receive emotional support or attention otherwise unobtainable. Finally, pain has not to be due to another mental disorder. Pain associated with muscle contraction headache is excluded because of the supposed pathophysiologic mechanism accounting for it.

In the description of other associated features of this category -such as the tendency to seek for medical help with a high frequency- the influence of the “somatization” model is evident. The model codified by Lipowski first in 1968 and then in 1988 as “the tendency to experience and communicate somatic distress and symptoms unaccounted for by pathological findings, to attribute them to physical illness, and to seek medical help for them.” (Lipowski, 1988. Quoted in Merskey, 2004: 68) *Psychogenic Pain Disorder* seems to inherit the main features of the old hysteria with specific reference to pain, although with a more marked focus on the patients' approach to the symptom, i.e. patients look at it as medical and not psychiatric problems, and therefore seek for medical treatment (in an exaggerated way). In the DSM-IV, *Pain Disorder* categorization is part of the more general category of *Somatoform Disorders*, that is defined by “the presence of physical symptoms that suggest a general medical condition (...) not fully explained by a general medical condition, by the direct effects of a substance, or by another mental disorder” (APA, 1994: 445); moreover, these symptoms must cause the individual



significant distress or impairment in important areas of functioning.<sup>33</sup> The validity of this category has been strongly debated in the psychiatric community, for various reasons: among these, the classification is strongly dualistic and forces a distinction between psychological and physiological aetiology, most of the more specific categories collected cannot be considered as valid ones and “appear to be part of a continuum that lack thresholds and are not associated with the psychological criteria one might expect in a psychiatric classification.” (Mayou, 2003: 450)

In the DSM-III revised edition, *Psychogenic Pain Disorder* changes into *Somatoform Pain Disorder*, whose diagnostic criteria are reformulated eliminating the need to prove the presence of psychological factors in pain aetiology. Moreover, a criterion is introduced requiring a “preoccupation with pain for at least six months” (Ballantyne, Fishman, Rathmell, 2009: 410), placing at the core of this entity the patient's pathological reaction to the pain and not the severity of pain itself. Again, physiopathological processes cannot account for pain, in the sense that a relation is not proved or that the patient's pain complaint is in excess with respect to physical findings.

#### *2.1.6 Current classifications of “psychogenic pain”*

Finally, in the DSM-IV (1994) “psychogenic pain” is classified simply as *Pain Disorder*, eliminating adjectives such as “psychogenic” and “somatoform”. Diagnostic criteria to define it are the presence of severe pain in one or more anatomical sites,

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<sup>33</sup> The conception of “psychogenic pain” as a somatoform disorder is even stronger in the proposal for the DSM-V as remarked in the next section

where “psychological factors are judged to have an important role in the onset, severity, exacerbation or maintenance of the pain” (APA, 1994: 458), the fact that the pain has to cause a significant impairment in individual's functioning, and the exclusion of other disorders. Moreover, the pain may be either associated solely with psychological factors or with psychological factors and a general medical condition. It is also required for the clinician to specify if the pain is acute or chronic (duration of at least six months).

In the International Classification of Diseases (ICD) by the World Health Organization (WHO), tenth edition, the relevant Pain Disorder diagnosis is *Persistent Somatoform Pain Disorder* in which

the predominant complaint is of persistent, severe and distressing pain, which cannot be explained fully by a physiological process or a physical disorder and which occurs in association with emotional conflict or psychosocial problems that are sufficient to allow the conclusion that they are the main causative influences. (WHO, 2010)

The ICD classification is clear at stating that there must be positive psychological evidence and the exclusion of an organic aetiology is not sufficient so that “if *the criteria are followed carefully, this diagnosis will rarely be made.*” (Merskey, 2004: 70) ICD does not specify what a physician is supposed to do when the patient reports persistent pain neither accountable for by an organic pathological cause nor by a psychopathological one, by implicitly indicating that a persistent pain conditions have inevitably to fit in a psychological categorization or in an organic one. Even if the ICD has not a diagnostic purpose as the DSM, the proposed classification of painful condition results unfulfilling, particularly because of a dichotomizing framework to

account for pain; as it will be showed with reference to chronic pain classification in the ICD, if the pain persists, but it not accountable for by a detectable damage, the condition is somehow unclassifiable. (See 3.2.2. *Chronic pain in disease classifications*)

### *2.1.7 Conclusion*

In conclusion, it seems that, even though the diagnosis of “hysteria” is no longer employed in the formal discourse of psychiatry, the APA’s classifications of “psychogenic pain” cannot be properly understood while disregarding the history of the classifications of those conditions previously categorized as “hysterical”. In particular, notwithstanding the several reformulations of “psychogenic pain” classification, this entity remains conceived in the psychiatric perspective as a somatic expression of a psychological issue internal to the patient. A noteworthy issue to remark, though, is the fact that, particularly with reference to persistent painful conditions, the psychological problems at play are seen as accounting either for pain’s causation and for its maintenance or exacerbation, by shifting the focus from the presence of pain to patient’s approach to it. Such a conception, considering as psychopathological the ways in which the sufferer relates to her pain, will characterize several psychological and psychiatric approaches to chronic pain as a pathological phenomenon in pain medicine, by giving way to consequent definitions of chronic pain as a disease. (See 3.1.6 *Chronic pain and behavior*, 3.1.7 *Chronic pain as abnormal illness behavior*, 3.1.8 *Chronic pain, abnormal illness behavior and*

*disability and 3.1.9 A controversial approach to chronic pain: the chronic pain syndrome)*

In the following pages, I will focus on the last classification of “psychogenic pain” in the DSM-IV, *Pain Disorder*. In this section I have presented a history of the main psychological conceptions of “psychogenic pain” after the second half of the XX<sup>th</sup> century; my main aim was to investigate if and how the standard classification of pain as a mental disorder in the DSM was related to the wider debate in psychiatry on “psychogenic pain”. In the next section, I will analyze the current classification of “psychogenic pain” in the DSM by disentangling and discussing the main problematical issues underlying this diagnostic category.

## *2.2 Psychogenic pain in the DSM: is Pain Disorder a valid classification?*

### *2.2.1 Introduction*

In what is conceived of as the first proposal of formal criteria for establishing the validity of psychiatric diagnoses (Kendell, Jablensky, 2003: 5), psychiatrists Robins and Güze list five of them: i) *clinical description*, that is the clinical picture of the disorder that may be one striking feature or more;<sup>34</sup> ii) *laboratory studies* (including chemical, physiological, radiological and anatomical findings as well as certain types of psychological tests considered reliable and reproducible); iii) *delimitation from other disorders*, based on exclusion criteria in order to distinguish the entity from other disorders sharing similar symptoms and other criteria allowing a differentiation

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<sup>34</sup> “Race, sex and age at onset, precipitating factors, and other items may be used to define the clinical picture more precisely.” Robins, Güze, 1970: 983

of the entity from borderline or doubtful cases; iv) *follow-up studies* to “determine whether or not the original are suffering from some other defined disorder that could account for the original clinical picture” (Robins and Güze, 1970: 984), and, finally, v) *family studies*. The last criterion is related to the fact that most psychiatric disorders run in families, so that a high prevalence of the same condition between relatives may indicate the validity of the clinical entity.

In this section, I will discuss the validity of DSM-IV classification of *Pain Disorder* by referring to the mentioned criteria,<sup>35</sup> in order to highlight some problematic issues rising from APA's last classification of “psychogenic pain”. In particular, I will question the validity of *Pain Disorder* as a clinical entity and I will show that APA fails in the attempt to dismiss a dualistic conception of pain. This last issue is particularly relevant in relation to the acknowledgment of chronic pain as a disease.

The clinical description of *Pain Disorder* indicates the presence of pain as an essential feature of this entity, as “the predominant focus of the clinical presentation (...) of sufficient severity to warrant clinical attention.” (APA, 1994: 459) Here, the stress is on the fact that this symptom has to be predominant: the authors of the chapter on “psychogenic pain” in the DSM-IV Sourcebook, King and Strain, highlight

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<sup>35</sup> Robins and Güze's criteria have been re-elaborated by Kendler (1980) who distinguishes between antecedent validators such as familial aggregation, premorbid personality and precipitating factors, concurrent validators and predictive validators (diagnostic consistency over time, rates of relapse and recovery and response to treatment. (Kendell, Jablensky, 2003, 5). More recently, Andreasen (1995) has proposed several additional criteria to Robins and Güze's ones in order to relate the symptoms to their neural substrates. However, as it will be discussed in the present section, *Pain Disorder* diagnosis' validity is already strongly challenged only by referring to Güze and Robin's criteria and this is the reason why other validity schemas are not taken in account

that in the previous categorization (*Somatoform Pain Disorder*) it was unclear how to define patient's "preoccupation with pain" and difficult to determine when pain was in excess with respect to what would be expected. *Pain Disorder* is differentiated by *Somatization Disorder* on the basis of the clinical description of the latter, which indicates that painful symptoms are only a part of the clinical presentation that has to include also gastrointestinal, pseudo-neurological and sexual symptoms.

Following the psychopathological description, in order to receive a *Pain Disorder* diagnosis, pain has to cause to the sufferer a "significant distress or impairment in social, occupational, or other important areas of functioning" where "psychological factors are judged to play a significant role in the onset, severity, exacerbation or maintenance of pain." (Ibidem)

### *2.2.2 Pain Disorder and the dualistic approach to pain*

Another crucial issue which King and Strain indicate as problematic is due to the fact that the classification *Somatoform Pain Disorder* entailed a dualistic view of pain, by distinguishing between organic and psychogenic pain<sup>36</sup>. In their view, this could suggest that the pain this category pointed to was "somehow different from pain from which there is an identifiable organic etiology" (King, Strain, 1996: 922), leading to the diagnosis being little used in research projects and in clinical practice. One of the reasons for that was the fact that this category -mainly based on the exclusion of a medical condition in a patient "preoccupied with pain"- could lead to

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<sup>36</sup> DSM-III R diagnoses was based on the acknowledgment of patient's preoccupation with pain where medical disorders were excluded

the risk of a stigmatization of the patient whose pain was supposed to be “psychogenic”<sup>37</sup> and “prevent the patient from receiving an appropriate treatment.” (Ibidem) To obviate this problem, in the DSM-IV categorization of *Pain Disorder* psychological factors are recognized as playing an important role in the condition and the clinician has to specify her assessment of their influence by indicating a particular subtype of the disorder: *Pain Disorder* associated with psychological factors, associated with both psychological factors and a general medical condition, or associated solely with a general medical condition; the last subtype is not conceived of as a mental disorder. In the DSM-IV Sourcebook it is specified that the first code (307.80) refers to a “psychological type”, in which pain aetiology is seen as mainly due to psychosocial factors and where if “a nonpsychiatric medical condition is present, it is judged to play no more than a minor role in accounting for the pain.” (King, Strain, 1996: 927)

*Pain Disorder* classification acknowledges that in the majority of painful conditions it is not possible to make a clear-cut distinction between a psychological aetiology and a medical one; furthermore, the status of psychological issues in this categorization remains blurred. First of all, there is no guidance in assessing when psychological factors are judged to play a major role and so indicate that this subtype should be diagnosed instead of the one in which they are supposed to be associated to a general medical condition. In the DSM-III, at least some indications were given,

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<sup>37</sup> The stigmatization is based on a supposed overlap between “psychogenic” label and “unreal” one, while it is obvious that no matter the aetiology of pain, in patient's perception pain is always real

such as a temporal relationship between pain onset and events producing psychological conflict, or a supposed “utility” of the pain in order to avoid something noxious to the individual or to obtain support.

Moreover, as Aigner and Bach remark, the presence of two specifications of the category seems to introduce a distinction between “pure’ psychosocially mediated pain and ‘mixed’ psychosomatic pain disorders.”<sup>38</sup> Hence, the supposed discarded dualistic approach to painful conditions returns in a more subtle way in DSM-IV classification. By specifying *Pain Disorder* subtypes, it seems in fact that an entity like a “pure” *Pain Disorder* exists that recalls the old notion of “psychogenic pain” as an exquisitely psychological condition, with the further acknowledgment that psychological factors may be involved not just at an etiological level but also as underlying pain maintenance.

As psychiatrist Sullivan highlights, the lack of positive criteria defining *Pain Disorder* or the supposed underlying mechanisms risks to make this categorization an empty concept. (See Sullivan, 2000)

The subtype including also the presence of a medical condition seems instead to refer mainly to chronic pain conditions in which usually psychosocial and physiological facts are deeply intertwined. In the DSM-IV Sourcebook, the authors of the section on *Somatoform Pain Disorder* argue that one of the reasons for the limited application in clinical practice of this classification is that this diagnosis “is not applicable to the majority of patients with chronic pain” (King, Strain, 1996: 922) and

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<sup>38</sup> Aigner, Bach, 1999: 356



the broadening of the DSM-IV category seems directed to the inclusion of these conditions. But is the pain that afflicts chronic pain sufferers what APA classifies as *Pain Disorder*?

As King and Strain report, chronic pain has been found to be “associated with virtually all Axis I diagnosis” (King, Strain, 1996: 923), both when there is no identifiable physical etiology for pain and when there is an organic pathology. However, it is acknowledged that when chronic pain patients suffer from a co-morbid psychiatric disorder this is normally a mood disorder such as anxiety and above all depression. (Aigner, Bach, 1999: 335)

In the section devoted to the Differential Diagnosis, it is claimed that when pain is associated with mood disorders, it is sufficient to make the latter diagnosis, e.g. Depressive Disorders, Anxiety Disorders or Psychotic Disorders. It seems therefore that *Pain Disorder associated with both psychological factors and a general medical condition* is a valid diagnosis only when it is recognized that the patient's pain is not due to a depressive or anxious state, although this assessment is very difficult to be made. Again, since APA speaks generally of “psychological factors”, how is it possible to understand whether the distressing and severe pain reported by the patient is associated, e.g., to a depressive state or to other not better specified psychological factors?

### *2.2.3 Pain Disorder and chronic pain*

Sullivan critically argues that the discussions about psychiatric disorders in chronic pain patients are “haunted by the concept of psychogenic pain” (Sullivan, 2000: 91)

that should account for those conditions unexplainable merely in terms of physical damage, but it turns useless since it is not defined by positive criteria nor are specific therapies proposed. Therefore Sullivan claims that in approaching chronic pain conditions, the use of *Pain Disorder* diagnosis should be avoided because it forces (again) the distinction between a medical or a psychological causation of the problem; Sullivan concludes that in these cases it would be better instead to employ mood disorders' classifications such as depression or anxiety for which at least effective treatments exist.

In his 2002 article, psychiatrist Boland remarks that a *Pain Disorder* diagnosis is rarely made in chronic pain clinics in which psychiatry does not play a major role; this disorder seems instead to be more common where psychiatrists and psychologists' presence is more prominent. Boland argues that -broadly conceived- *Pain Disorder* associated with psychological factors and a general medical condition may well describe most of chronic pain conditions, but this over-inclusiveness may make this categorization useless.

In encompassing all pain patients, there seems to be no clear way to distinguish the cases that are of particular psychological concern, and the decision to use a psychiatric diagnosis appears to be a subjective one, dependent on the philosophy of the diagnostician. (Boland, 2002: 25)

The problematic status of *Pain Disorder* classification may be the reason why this diagnosis, as well as *Somatoform Pain Disorder* one has been rarely employed in clinical settings. In a review of the existing scientific literature, Boland remarks that in most chronic pain studies different nomenclatures are preferred to APA's one, and, when research studies focus specifically on psychiatric disorders related to pain, the interest is mainly on the comorbidity of chronic pain with anxiety and depression.

By focusing on *Pain Disorder's* delimitation from other disorders, we read that for the differential diagnosis when pain is associated to mood disorders (depression, anxiety) or psychotic states, "an additional diagnosis of Pain Disorder should be considered only if the pain is an independent focus of clinical attention, leads to clinically significant distress or impairment, and is in excess with that usually associated with the other mental disorder." (APA, 1994: 461) Moreover, the pain must not be a conversion symptom (which would require a classification as *Conversion Disorder*) and must not be intentionally produced or feigned as in *Factitious Disorder* (intentional production of physical or psychological signs or symptoms in order to assume the sick role) and *Malingering* (intentional production of false or exaggerated physical or psychological symptoms motivated by external incentives such as avoiding duties, etc.) Finally, the pain must not occur during the course of *Somatization Disorder* even though Aigner and Bach emphasize that clinically "the differentiation of particular somatoform disorders according to DSM-IV remains questionable" (Aigner, Bach, 1999: 355) because of the high rate of symptomatological overlap between these conditions.

From this critical review, we can conclude that *Pain Disorder* is theoretically delimited from other conditions, but accepting these constraints leads to the claim that, if there is such an entity as *Pain Disorder*, we have no idea of the psychopathological mechanisms involved in its production and its relationships with concomitant disorders, above all in chronic pain. In this sense the validity of *Pain Disorder* is questionable: even without being committed to a “disease realism” that would require the indication of the psychopathological mechanisms underlying the condition, however this diagnosis is not well defined by “the existence of clear boundaries or qualitative differences” from other disorders. (Kendell, Jablensky, 2003: 8)

The *Pain Disorder* classification seems (again) to be a classification mainly grounded on exclusion criteria without a positive description of the entity, which makes it look more like an artificial construct used to account for poorly understood painful conditions than a nosological entity in its own right. As Sullivan argues, “perhaps the most serious problem with *Pain Disorder* is the implication that pain is a mental disorder” (Sullivan, 2000: 92) and, even though in the DSM-IV the effort to minimize the extent of this conception of pain is clear, “the very inclusion of the diagnosis in the manual of mental disorders undermines this effort.” (Ibidem)

#### *2.2.4 The future of Pain Disorder: some concluding remarks*

In the draft proposal for the DSM-V, DSM-IV *Pain Disorder* is subsumed under the more general category of *Complex Somatic Symptom Disorder* (CSSD) whose clinical presentation is based on three main criteria: i) the presence of one or more

somatic symptoms causing distress or resulting in significant disruption of daily life, ii) the presence of “excessive thoughts, feelings, and behaviors related to these somatic symptoms or associated health concerns” (APA, 2010) and iii) the condition's chronicity (assessed when the symptom lasts more than 6 months). Moreover, specifications may be *optionally* added when a particular symptom, e.g., pain, dominates the clinical presentation and is in strong relation to criterion ii). If the presence of pain is not associated to this criterion, it is recommended to evaluate the condition as *adjustment disorder* (where a stressor is recognized as causing a psychopathological reaction), or to conceive of it as a case in which *psychological factors affect a medical condition* (in which the influence of psychological factors has to be proved<sup>39</sup>). Beside *Pain Disorder*, CSSD includes also *Combined Somatization Disorder*, *Hypochondriasis* and *Undifferentiated Somatoform Disorder*. This proposal is motivated by the common feature shared by these conditions, i.e. the clinical presentation of somatic symptom and/or concern about medical illness. Moreover, in the footnote it is claimed that these conditions are grouped for “purposes of clinical utility (these patients are mainly encountered in general medical settings), rather than assumptions on shared etiology or mechanism. (APA, 2010)<sup>40</sup> Many psychiatrists

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<sup>39</sup> The diagnosis of *psychological factors affecting a general medical condition* is made when a) a general medical condition is present and b) psychosocial factors are judged to affect it. The influence of psychological factors is assessed on the basis of: a temporal relationship between psychological factors and the development of the condition, the exacerbation or delayed recover from the medical condition, when these factors interfere with the treatment or finally, when these factors are seen as causing an additional health risk for the individual or influence the underlying pathology by precipitating or exacerbating its symptoms

<sup>40</sup> APA, 2010

have expressed a general dissatisfaction in relation to the classification of somatoform disorders in the DSM, and particularly of “psychogenic pain” as part of it. The main relevant issue of the conditions which will be reunited in the Somatic Symptom Disorders category, as indicated in the DSM-V draft proposal, is the fact that they are frequently encountered in medical settings and that, more often, these patients are not addressed to a specific psychiatric treatment. (See Mayou, Levenson, Sharpe, 2003) In this sense, this categorization is not grounded on the recognition of a psychological underlying issue, but on their unaccountability by a solely organic framework.

In APA's draft proposal, *Pain Disorder* (and also the other somatoform disorders) occurs now as a particular specification of a broader condition in which somatic distressing symptoms are related to the patient's maladaptive behavior or to an exaggerated health concern in relation to it. “Psychogenic pain” thus loses its autonomy, but in this way it seems to fit better with scientific research findings indicating a frequent overlap between somatoform conditions. In this renewed classification, problematic issues afflicting “psychogenic pain” diagnosis and concerning the specification of how psychological factors actually cause the conditions or the dualistic conception of pain are no longer taken into account. If this draft proposal becomes effective, a questionable definition of pain as a psychiatric disorder will persist, perhaps due to the ongoing strength of the historically dominant view of pain (that the DSM-IV classification attempted to hide), i.e. that when pain is inconsistent with physical findings, it is a psychopathological phenomenon.

The analysis of the issues involved in the classifications of pain as a mental disorder underlie the discussion on the acknowledgment of chronic pain as a disease which will be presented in the next chapter. The persistence of pain without a detectable organic damage accounting for it is a crucial issue in the biomedical conceptualization of chronic pain as a pathological phenomenon. This question will be tackled with a focus on the ways in which chronic pain has been constituted as a morbid entity inside pain medicine, where the co-occurrence of several perspectives will entail also the formulation of different definitions of the pathologic character of chronic pain, strongly related to the interpretations of the role played by psychopathological issues in this condition. Furthermore, it will be highlighted how the divide between organic and psychological conceptions of pain's causation still influences biomedical approach to chronic pain. Moreover, the stress on the sufferer's maladaptive behavior will return in the interpretation of chronic pain as a morbid entity inside pain medicine, and will be therefore discussed more in-depth.

## Chapter 3

### PATHOLOGICAL PAIN: CHRONIC PAIN AS A DISEASE

#### *3.1 What is chronic pain?*

##### *3.1.1 Introduction*

As previously remarked in relation to “psychogenic pain”, the definition of pain as a pathological entity represents a noteworthy issue in biomedicine. The present section deals with this question by focusing on the acknowledgment of chronic pain as a disease in biomedicine, and, specifically, in pain medicine.

In the medical literature, chronic pain is generally defined as the pain that lasts longer than the usual course of an acute injury or disease; generally, this period is assessed to be six months. The broadness of this definition witnesses the difficulty of defining chronic pain as a morbid entity in its own right. The aim of the present section is to discuss this issue by recalling the history of the constitution of chronic pain as a disease.

The way in which chronic pain has been defined as a specific object interest in biomedical knowledge, and especially, as a disease, is deeply bounded to the constitution of a new branch of medicine, that is pain medicine. In the second half of the XX<sup>th</sup> century, a movement takes place in the US which will lead to the creation of the IASP and to the constitution of a new field of medicine, primarily devoted to the study and the management of pain. The history of the constitution of this medical specialty has been reconstructed by the sociologist of medicine Isabelle Baszanger,



who has devoted an entire book to this topic (Baszanger, 1998). In this section, starting from Baszanger's account of the different steps which have led to the rise of pain medicine, I will focus on a precise object which is crucial in the shaping of this new discipline, chronic pain. In particular, I will focus on the ways in which chronic pain has been constituted as a pathological entity in pain medicine.<sup>41</sup> First, I will refer to Bonica's pivotal textbook on the management of pain by analyzing the ways in which chronic pain has been gradually acknowledged as a pathological entity in the different editions of the book. I will then consider the different ways in which psychopathological features of chronic pain have been conceived of in the rising pain medicine, giving way to the formulation of different notions of chronic pain as a disease. In this regard, I will examine two concepts, abnormal illness behavior (AIB) and chronic pain syndrome (CPS), which share some debatable issues with psychogenic pain categorization. The problematic acknowledgment of chronic pain as a disease is not just a theoretical matter, but becomes particularly relevant in relation to disability claims, above all in an healthcare system such as the US one, and increasingly also in the European context.

### *3.1.2 Pain as a medical problem*

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<sup>41</sup> In this chapter, I often employ the terms "constitute" and "constitution" in relation to the way in which chronic pain has "emerged" as a pathological entity in pain medicine. My linguistic choice is due to the attempt to highlight that the fact that nowadays chronic pain is –at least formally- considered as a disease in itself is the result of an operation which has led to the "creation" of a new conception of pain, and, especially of chronic pain, as an object of concern in biomedicine

In her 1995 work<sup>42</sup>, sociologist Baszanger shows how chronic pain has been constituted as a primary object of concern inside the burgeoning pain medicine. Baszanger remarks that this operation has been grounded on a wider one, that is the recognition of the problematic status of pain itself in medicine. The main promoter of this change of perspective on pain is the American anesthesiologist John J. Bonica, the author of *The Management of Pain*, which is still nowadays so-to-speak the Bible of pain specialists. From the first edition of his work (1953), Bonica argues for the necessity of a shift in biomedical conception of pain from an understanding of the phenomenon solely as a symptom of an underlying disease, to a wider view of pain as a problem in itself. This renewed perspective entails the acknowledgment of the fact that pain is a major medical issue -still unsolved- on which physicians have to “act (...) as they would do for any other pathological condition.” (Bonica, 1953. Quoted in Baszanger, 1998: 27)

The renewed approach to pain pursued in pain medicine is underlied by important socio-economical issues affecting US (as well as other so-called developed Western countries) in the second half of XX<sup>th</sup> century<sup>43</sup>; among these, a major one is the acknowledgement of the economic burden for the society represented by chronic conditions (Bonica, 1990: 181-183). According to Bonica, the huge cost of chronic pain is scarcely taken in account because of a lack of epidemiological data assessing the socio-economical incidence of these conditions. In 1990, Bonica remarks that

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<sup>42</sup> Baszanger, 1998 is the year of the English translation

<sup>43</sup> Baszanger indicates many reasons accounting for this change of perspective on pain in medicine. See Baszanger, 1998: 42-47

there was still a paucity of studies evaluating the prevalence of chronic pain conditions in the general population<sup>44</sup>. From a first review of the literature available, however, Bonica and colleagues estimate that more than one-third of the American population in 1986 suffered from chronic pain syndromes and that the 50-60% of them was partially or completely invalid from period varying from days to a permanent disability. In the 2001 edition of Bonica's textbook, Jacobson and Mariano report that current evaluations of chronic pain' incidence indicated that the 10% of Americans had pain on more than 100 days every year, leading the majority of them to disability. (Jacobson, Mariano, 2001: 241) For what it concerns Europe, a well-known 2006 survey on chronic pain prevalence in European Countries indicates that chronic pain is one of the major health care problems. (See Breivik et al., 2006)

In his 1953 textbook on pain and its treatment, Bonica is concerned in particular with those persistent pains that continue even when the supposed cause is treated; among these conditions, phantom limb pain, the so-called pains without lesion and in general, those pains without a clear recognizable cause, which represent the most striking evidence of a failure of biomedical traditional approach to pain.<sup>45</sup> According to the author, the main troubling feature of these pains is the fact that, in persisting, they

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<sup>44</sup> The first important epidemiological studies on chronic pain incidence with a specification of the most prevalent chronic pain syndromes came out in these years: the Nuprin Pain Report in 1985, a telephone survey run in the US on 1254 people and the study run by Crook and colleagues in 1984 based on interviews to 372 Canadian families

<sup>45</sup> In this case, the "traditional biomedical model" to which I refer to is that which sees pain solely as the symptom of an underlying organic disease; in this perspective, therefore, when the morbid condition is treated, pain should also vanish

give way to pathological psychophysiological reactions<sup>46</sup> that may create a vicious circle and make therefore these painful conditions treatment resistant. Furthermore, especially for such problematic conditions as causalgia, trigeminal neuralgia and cancer-related pains, the duration of pain is a fundamental aspect to consider: when pains with a certain degree of intensity persist, their negative influence on the individual is huge. Chronic pain may exhaust the patient and cause a loss of appetite, sleep, fear, worry and anxiety. As Bonica highlights, even when the pain does not produce observable physical problems, “the mental disturbances, manifested by irritability of the temper, neurasthenia, and even psychoneurosis, are manifold, and remain more or less persistent even after the prolonged painful syndrome has entirely and permanently disappeared.” (Bonica, 1953: 156) This aspect, Bonica highlights, is particularly relevant in a clinical perspective since these conditions are frequently encountered in the clinical practice and it is fundamental to recognize that the development of psychoneurotic conditions in these patients is usually the effect and not the cause of prolonged pain. An early treatment of persistent pain is therefore crucial in order to avoid such devastating consequences on the individual.

In the first edition of Bonica’s textbook, the label “chronic” is rarely mentioned whereas adjectives such as “abnormal” and “intractable” are preferred in speaking of persistent painful conditions such as causalgia (Bonica, 1953: 128). When the first edition of Bonica’s textbook was put forward, the idea that persistent pain had a

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<sup>46</sup> In the 1953 edition, Bonica devotes an entire chapter to this question, “The mental and physical effects of pain”

specific characterization, distinguishing it e.g., from acute pain, was not yet formally stated. In the 1953 edition, Bonica was more concerned with the acknowledgment of clinical pain, i.e. the pain encountered in the clinical practice, and of its peculiarity in relation to the pain studied in the laboratory. It is precisely the recognition of the gap between “experimental pain” and the pain encountered in the clinical practice which will ground the reflection on chronic pain and the conclusion that this condition has to be conceived as a pathological entity in its own right.

Chronic pain will be presented as an autonomous entity from the second edition of *The Management of Pain* (1990), in which a section is devoted to the topic.

### *3.1.3 Chronic pain as disease in Bonica's Management of Pain*

In his 1953 textbook, Bonica claims that there are some types of pain which have to be considered as pathological phenomena requiring a specific therapeutic approach. Here, Bonica takes a pragmatic stance and argues that

pain in certain instances serves as a physiologic function while in other cases is a pathological entity (...) I interpret pain in its initial phase as a physiological sensation with the function of warning the organism that its integrity is disturbed and in danger; whereas in its late phases, when it becomes intractable, it no longer serves a useful purpose and then becomes, through its mental and physical effects, a destructive force. (Bonica, 1953: 76)

In Bonica's first definition, the gap between “normal” and “abnormal” pain lies in the distinction that biological nature itself sets: normal pain has the function of signalling the presence of a damage occurred and it is therefore useful to the organism to prevent further risks; abnormal pain is instead the pain which has lost its protective function and persists without any purpose.

In the first edition of the textbook, chronic pain is not yet recognized as an autonomous entity and pathological pains are characterized as those deviating from physiological norms: they are useless for the organism and, in persisting, they give way to pathological physiologic and psychological reactions which are very difficult to handle through traditional therapeutic means, also because of a lack of knowledge at that time of the mechanisms perpetrating these pains. In Bonica's first analyses, the disease status of chronic pain is therefore mainly grounded on the acknowledgment of the devastating consequences of persisting pain for the sufferer. In 1974, Bonica defines chronic pain as an evil force, exclusively malefic with no redeeming features (Bonica, 1974. Quoted in Craig, 1984: 838), that neither follows natural laws<sup>47</sup> nor is easily treatable, becoming therefore a problem both for physicians and for patients and their environment. Furthermore, the effects of these pains

both physical and mental, cannot be considered as occurring separately, for they involve the same protean and complex physiopsychological processes. The whole subject of pain, including its effects, must therefore be considered and approached clinically as a psychosomatic problem. (Bonica, 1953: 154. Quoted in Baszanger 1998: 27)

Here, Bonica's purpose -to force physicians to recognize persisting pain as a disease in itself and not as a symptom of another condition- is pursued by recalling surgeon René Leriche's conception of *douleur maladie*. In his work *The surgery of pain*, Leriche expressly refuses to consider pain a physiological sensation, and defines it for the first time as a pathological phenomenon. Leriche claims that pain

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<sup>47</sup> Here Bonica seems to refer to the physiological function of pain, that of being an alarm indicating the presence of a damage

does not have any sense nor is a sense, unless it is considered in relation to human individuality. “Physical pain is not a simple question of nerve impulses moving at a fixed speed along a nerve. *It is the result of the conflict between a stimulant and the individual as a whole*” (Leriche, 1940: 488). Leriche’s aim is to force physicians to abandon the conception of pain as a natural and therefore somehow acceptable, disease-related fact, emphasizing its being inseparable from the sufferer: pain is *douleur maladie* (pain-disease) because pain is “a monstrous individual phenomenon and not a law of the species. A fact of disease” (Leriche, 1940: 490). This criticism of the standard medical view of pain has a broader scope than just a philanthropic memento of the tragedy of individual suffering, for Leriche sees individual pain as something that is somehow “created” by the sufferer. As epistemologist Georges Canguilhem remarks, Leriche's conception of pain-disease involves the “total coincidence of disease and the diseased person” (Canguilhem, 1978: 51). Hence, pain is not something that happens to the individual, but an event that involves and is always shaped by the sufferer in her complexity. The aim of Bonica at that time (in 1953) is precisely to bring about this change of perspective on pain phenomenon and to force physicians to conceive of it as a complex clinical entity in which physiological, psychological, and socio-cultural factors are always interrelated and, therefore, have to be approached as a whole.<sup>48</sup>

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<sup>48</sup> In the first edition of *The Management of Pain*, Bonica already refers to Leriche’s considerations on abnormal pains (Bonica, 1953:76). This author is a well-known physician (surgeon) who has dealt with those abnormal painful conditions and has indicated the necessity of a change of perspective on pain phenomenon in

In the 1990 edition of *The Management of Pain*, Bonica devotes an entire chapter to chronic pain and defines it as the pain “which persists a month beyond the usual course of an acute injury or disease or reasonable time for an injury to heal, or pain that recurs at intervals for months or years.” (Bonica, 1990: 180) Furthermore, Bonica points out that the indication of six months is approximate, because the expected healing time for some painful conditions may be shorter. The characterization of chronic pain as a distinct entity is made here mainly on the basis of the distinction between acute and chronic pain. The difference between persistent and acute pain is not solely temporal, but set on the basis of major differences in “etiology, mechanisms, pathophysiology, symptomatology, diagnosis, therapy, and, most importantly, biologic function.” (Ibidem) In a 1974 work on pain patients, psychiatrist Sternbach remarks that the differences between these two types of pain are grounded on observable and relevant physiological, psychological and behavioural issues. Acute pain normally vanishes after healing, whereas chronic pain is defined by the fact that pain persists after healing and may even spread to other body areas. This is the main reason why chronic pain has to be conceived of as a disease in itself and not as a symptom of an underlying disease. For what it concerns aetiology, Bonica claims that

chronic pain is caused by chronic pathologic processes in somatic structures or viscera, or by prolonged and sometimes permanent dysfunction of the peripheral or central nervous

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medicine. In this sense, the authority of Leriche is fundamental for Bonica’s aim of remarking on the necessity of a different approach to some painful conditions



system or both, and, in contrast to acute pain it can also be caused *primarily* by psychological mechanisms and/or environmental factors. (Bonica, 1990: 181)

Moreover, physiologic, affective and behaviour responses to chronic pain vary from those pertaining acute pain. Finally, unlike the majority of acute pain conditions, chronic pain is always deviant from biological normativity.

In the 2001 edition<sup>49</sup> of *The Management of Pain*, chronic pain is finally defined as the pain that may be caused by an injury or a disease but which persists because of factors that are “both pathogenetically and physically remote from the originating cause.” (Turk and Okifuji, 2001: 17) In conditions such as mechanical back pain and fibromyalgia syndrome, on which I will focus in the last chapter, the gap between the underlying pathology and the severity and the persistence of pain is evident. Here, the definition of chronic pain is no more grounded on the distinction between acute and chronic pain, but it recognizes chronic pain as an autonomous entity characterized by a deep gap between pain and the causes which have primarily triggered it.

The acknowledgment of a lack of a direct and locally definable relationship between the initial cause of pain and chronic pain seems to be related to an advancement in the scientific knowledge of the pathological mechanisms underlying persistent pain. In this edition of the textbook, it is claimed that chronic pain without a discernable organic cause may indeed be accounted for by the presence of a physiopathological mechanisms that entail a sensitization of the peripheral or CNS, in

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<sup>49</sup> The last edition of Bonica’s textbook (2010) does not differ significantly to the third one in the definition of chronic pain and its mechanisms

conjunction with a predisposition of the individual due to genetic factors and prior life experiences, which may account for a persisting pain following an initial insult. Social and psychological factors are seen as relevantly interacting with the nervous system, and may therefore contribute to “the persistence of pain and associated illness behaviour.” (Ibidem) This conception refers to the mechanism of the so-called central sensitization, that is an increase of neuronal responsiveness caused by a prolonged activity of dorsal horn neurons consequent to repeated or sustained noxious stimulation. This framework has proved itself to be particularly helpful in explaining the complexity of chronic pain syndromes, above all those conditions not accountable for by discernable tissue damage. Central sensitization is often employed to explain problematical conditions such as fibromyalgic syndrome, characterized by widespread chronic pain and by other symptoms accountable for by the presence of a neurological dysfunction such as fatigue and mood disorder. In chapter IV, I will discuss the way in which this neurophysiological model of disease is employed in relation to fibromyalgia and other elusive conditions such as chronic fatigue syndrome.

#### *3.1.4 The ambiguous status of psychological factors in pain medicine*

As already anticipated, the different interpretations given to the role played by psychopathological factors in chronic pain strongly characterize the constitution of chronic pain as a disease in pain medicine. The co-occurrence of several perspectives participating to the creation of this new biomedical specialty and working at the definition of its object, leads also to the presence, inside pain

medicine's movement, of different conceptualizations and approaches to chronic pain as a disease. In the following sections, the most prominent perspectives will be tackled and their contributions to the definitions of persistent pain as a pathological entity will be analyzed.

Beside purely psychological and psychiatric approaches to chronic pain, the issue of the role played by psychological factors in chronic pain has influenced in a wider and deeper way pain medicine's approach to pain, indicating e.g., the necessity to approach chronic pain sufferers in a comprehensive perspective, by evaluating also the patients' personal histories and their social environment. The influence of psychopathological factors in persistent pain has also been interpreted by some authors as the crucial issue defining chronic pain's pathological status; such conceptions have led to the formulation of troublesome definitions of chronic pain conditions as wholly psychological, characterized by issues already analyzed with reference to "psychogenic pain".

In the first edition of his handbook, Bonica gives a general classification of pain: pain may be of peripheral origin, of central origin, or psychogenic. The first type of pain is usually initiated by an organic disturbance of pain receptive mechanisms while the second one is the result of a dysfunction of a part of the central nervous system. In Bonica's words, psychogenic pain is instead "a term restricted to a group spoken of by the sufferers as pain, of which it may be said that no satisfactory organic etiology can be found." (Bonica, 1953: 134) Here, Bonica clearly draws a distinction between psychogenic and organic pains grounded on their aetiology, but,

at the same time, attempts to weaken such a clear-cut differentiation by employing a descriptive characterization of these pains. Bonica does not claim, indeed, that psychogenic, functional, psychic pains have a psychological aetiology, but that these pains are those reported by the patients which cannot be accounted for (on an external observer's judgement, e.g. the physician) by a physical disease or injury. This absence of organic findings leads to the conclusion "that the pain in 'psychic in origin.'" (Ibidem) As Baszanger remarks, psychogenic pain has a peculiar status in Bonica's first classification, being the only pain identified on the basis of patient's claim (to be in pain) and not in relation to the hypothesized underlying mechanisms. A similar classification of "psychogenic pain", which attempts to weaken an ultimate aetiological distinction between organic and psychogenic pains by according epistemic authority to the sufferer, is that of IASP's definition of pain<sup>50</sup>.

In the first edition of the textbook, the relevance of defining psychogenic pain is related to Bonica's concern of a proper identification of these conditions in the clinical practice<sup>51</sup>; too often, the anesthesiologist complains, mental effects of pain persistence are seen as causes of the pain itself. This view may lead to a dismissal of chronic painful conditions, because they are seen as psychogenic by the physician, who may therefore conclude that she cannot do anything for these patients. In attempting to force practitioners to deal with persistent painful conditions and to acknowledge their complexity, Bonica stresses instead that clinical pain has to

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<sup>50</sup> See 2.1 *What is pain? IASP's definition of pain*

<sup>51</sup> A similar preoccupation is made explicit by Merskey, 1968 in the same paper in which the draft of IASP's definition of pain is presented. See section 1.2 of the present work

be “considered as a fundamentally psychobiological phenomenon which is not easily classified as either a sensation or an emotion” (Bonica, 1953:135). The common habit of seeing an overwhelming gap between organic and psychic pain -with the further characterization of the latter as unreal or imaginary- fails when confronted with the evidence that “pain, whatever its source or origins, is in the final analyses a psychic event” (Ibidem). This definition of pain phenomenon refers to the conception of pain widely shared in the scientific community at that time as compounded by two main phases, perception and reaction.<sup>52</sup> While the former aspect of pain is seen as a neurologic process, the reaction is wholly emotional and, therefore, a psychic phenomenon. In clinical painful syndromes, the contribution of neurologic and psychic aspects to the potential pain spectrum may vary from a pure organic pain condition, in which there is a predominance of the neurologic aspect of pain and the psychic reaction is minor (this is defined as a “normal reaction”), to a psychogenic pain condition, when the pain is “resulting from the projection of psychic conflict to some organ without any abnormal activity or tension in the organ to which the pain is referred.” (Bonica, 1953: 137)<sup>53</sup> These pains are usually reported by obsessive neurotics or psychotic patients and are related to an underlying anxiety or guilt. In Bonica’s perspective, as “organic pain” is a message of the organism that something

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<sup>52</sup> See 1.2.2. *Before IASP’s definition: pain as perception and reaction*

<sup>53</sup> See the diagram of Pain Spectrum reported by Bonica, 1953: 136

is injured and that therefore something has to be done; “psychogenic pain” is also a message, indicating that something is not well with the psyche.<sup>54</sup>

As Baszanger remarks, Bonica's initial representation of pain recognizes a double role of psychological features as components of every pain and as causes of a particular type of them, psychogenic pain. The acknowledgment of the first aspect, that every pain has a strong emotional aspect, which is especially noteworthy in persistent pain conditions, is aimed at stating that chronic pain has to be approached in its complexity and therefore “the physician (...) should assume the responsibility of evaluating the personality (...) as well as the physical examination.” (Bonica, 1953: 137) The double value of psychological factors in pain, particularly in persistent pain, originates an ambiguity which will be “handled differently in the various phases of development of pain medicine” (Baszanger, 1998: 37) and will give way to several interpretations of chronic pain as a disease. Furthermore, even if from the second edition of Bonica's textbook, pain will be not classified anymore on the basis of such a strong distinction between psychogenic and organic, the definition of pain as psychogenic will not be abandoned by Bonica. In the second edition of his textbook, Bonica claims that unlike acute pain, chronic pain may also be induced by psychological or environmental mechanisms. (Bonica, 1990: 183)

From the second edition of *The Management of Pain*, the sections devoted to psychopathological aspects of pain will be dealt with by psychologists and

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<sup>54</sup> The conception of “psychogenic pain” as a communication tool has been discussed in the previous section. See 2.1.3 *Pain as a communication tool*

psychiatrists. Sternbach, one of the most prominent psychiatrists of pain medicine movement, indicates that psychopathological factors causing chronic pain are four: psychophysiological mechanisms, learning (operant) mechanisms, psychologic (psychogenic) mechanisms, and psychiatric mechanisms. The first one refers to those conditions such as chronic tension headache in which the pain is caused by psychophysiological factors, e.g. stressful events which generate physiological reactions causing pain. (See Sternbach, 1990: 287) Psychologic pain mechanisms are indicated as those underlying those chronic pain conditions and which are classified in the DSM (at that time, DSM-III-R) in reference to those patients suffering from a *Somatoform Pain Disorder*. Bonica describes these patients' pain as "psychological", i.e. "less adequately explained in physical terms given current models of brain function." (Bonica, 1990: 189) Psychiatric mechanisms causing pain are those noticeable in patients suffering from schizophrenia, conversion hysteria and, more often, in chronic pain conditions, related to depression. Schizophrenic hallucinatory pain is not taken in consideration in this work because the diagnosis of schizophrenia usually entails a purely psychiatric interpretation of pain and therefore has not been taken in account in pain medicine's debates on chronic pain. The relationship between pain and conversion hysteria has been already discussed in the first section of the dissertation<sup>55</sup>, while the link between chronic pain and depression is analyzed in the last section of the present chapter as a relevant issue related to the

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<sup>55</sup> See 2.1 A History of psychogenic pain

acknowledgment of chronic pain as a disease.<sup>56</sup> In the following sections, I focus on operant conditioning model and on the definition of abnormal illness behavior (AIB), both models put forward to account for problematic painful conditions which focus on the patients' behaviors as the pathological element characterizing some chronic pain conditions. Even if nowadays these psychological conceptions are less frequently employed in discourses about psychopathological issues in chronic pain, they had a relevant fortune in the constitution of chronic pain entity. Moreover, the stress of learning-operant model and of AIB notion on chronic pain patient's way to approach her own pain still remains a pivotal issue in the biomedical perspective on chronic pain. A more in-depth analyses of this topic is presented in the IV chapter of my thesis, in relation to fibromyalgic syndrome.

### *3.1.5 Chronic pain as the object of pain medicine: a new look on pain*

The first international symposium on pain held in 1973<sup>57</sup> was the occasion for specialists working in the field to meet, exchange views, and set the main outlines of what would become pain medicine. Here, professionals belonging to different domains such as neurophysiologists, anesthesiologists, psychologists and clinicians met and presented their perspectives on the topic of pain.

In his speech, Bonica stressed the negative incidence of chronic pain on the sufferers' lives and as a major socio-economical problem. In Bonica's view, chronic pain remained an unresolved issue for three main reasons: a lack of knowledge

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<sup>56</sup> See 3.2.6 *Chronic pain and depression: a digression*

<sup>57</sup> The symposium was funded by private groups (pharmaceutics companies included), by the University of Washington and by three different divisions of the NIH



about the pathological mechanisms of chronic pain, a lack of medical training thwarting chronic pain patients to receive appropriate treatment, and a lack of communications between different specialists working in the field of pain. The Congress was also the occasion for Bonica to present his idea of the pain clinic, a multidisciplinary framework presented as the most appropriate therapeutic solution to the complexity of painful conditions. (See Baszanger, 1998: 70) This model had already been experimented by Bonica on a small scale with the collaboration of a surgeon and a nurse at the University of Washington in Seattle, where he had been nominated in 1960 Head of the Anesthesiology Department. The idea of a multidisciplinary integrated approach pursued in a specific clinic took about twenty years to shift from a local project to a more widespread movement.<sup>58</sup>

As Baszanger remarks, Melzack and Wall's Gate Control Theory of pain mechanisms was the theoretical tool setting a common ground in the first meeting for clinicians and researchers to bring to the constitution of pain medicine<sup>59</sup>. At the Congress, Melzack himself explained that, on the basis of scientific knowledge of pain mechanisms, an action directed solely to the sensory component of pain was useless.<sup>60</sup> A new conception of pain treatment was needed: not to abolish pain sensation but rather to reduce it to a tolerable level and in some cases "teaching

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<sup>58</sup> The issue of the multidisciplinary approach to chronic pain conditions will be discussed in the next chapter in relation to the problematic therapeutic approach to fibromyalgic syndrome

<sup>59</sup> See 1.1 *The discovery of pain as a multidimensional entity*

<sup>60</sup> In 1968, Melzack in collaboration with Casey extends the Gate Control model presented in 1965 with Wall by indicating that pain is determined by the activity of three parallel systems: the gate control system, the motivational-affective system and the sensory discriminative one

patients how to live with their pain” (Melzack, 1974. Quoted in Baszanger, 1998: 74)

In order to achieve this goal, Melzack stressed the importance of psychological approaches to in conjunction with physiological techniques. Among these, hypnosis, operant conditioning as well as psychotherapy and pharmacological approaches were indicated as potential means to help the patients to deal with pain.

### *3.1.6 Chronic pain and behaviour*

The operant conditioning approach to chronic pain is presented at the 1973 conference by psychiatrist Wilbert Fordyce. Fordyce proposes to conceive of chronic pain as a behavior, thereby challenging what he sees as the traditional medical disease model grounded on the idea that the patient's pain is the symptom of “some process lying within the person.” (Fordyce, 1984, 865) In this framework, therapeutic action is addressed to the treatment of what is supposed to be the cause of pain, instead of pain itself. If it is not possible to find the pathophysiological mechanism causing pain, the clinician usually concludes that the problem must be in the patient's mind. On a behavioural perspective such as Fordyce's, instead, the patient's pain is the same thing as the patient's pain behavior. These behaviors may be “respondent” or “operant”: while the first ones involve autonomically mediated responses and represent therefore reactions to stimuli, operant behaviours are actions involving voluntary muscles and “sensitive to learning or conditioning effects from contingent reinforcement.” (Ibidem) If an operant behaviour is followed by a reinforcing consequence, it will often occur, while if it is followed by an adverse consequence, its frequency will decrease. By applying this model to clinical pain, Fordyce suggests to

suppress positive reinforcers to pain behaviour, such as getting attention from other people, avoiding duties and increasing drug administration, and increasing instead those behaviours incompatible with pain ones. This work has to be done by acting in particular on the patient's environment, mainly the family, by evaluating which factors may induce the maintenance of the pain behaviours. Fordyce's model had a noteworthy resonance, since in 1990 edition's presentation of the "multidisciplinary, multimodal approach to chronic pain" and of the pain clinic model, his techniques to deal with chronic pain (and to teach patients how to deal with their pain) are indicated as fundamental aspects of the integrated approach pursued by Bonica and colleagues. (Bonica, 1990: 2107-2119)

Nowadays, a mitigated cognitive-behavioural conception of the psychopathological mechanisms underlying chronic pain is noticeable in approaches such as the "fear-avoidance model", quite prominent in pain research, above all in relation to musculoskeletal pain conditions. (See Lethem et al., 1983 and Vlayen and Lynton, 2000. Quoted in Loeser, 2001) This model aims at explaining the mutual relationships between pain and anxiety: when chronic pain sufferers experience fear or anxiety in relation to their pain, they may consequently start avoiding the pain and related situations, e.g. specific movements or activities which may increase their pain; this may result in increasing emotional impact of pain and the severity of their disability. In these situations, a cognitive-behavioural therapy (CBT) is proposed to deal with the several functional limitations characterizing some chronic pain conditions.

### *3.1.7 Chronic pain as abnormal illness behaviour*

In the 1990 edition of *The Management of Pain*, in the section devoted to the chronic pain syndromes of psychologic and psychosocial origin, Izzy Pilowsky's intervention on chronic pain and illness behaviour is included. (Pilowsky, 1990: 300) The concept of illness behaviour was introduced in 1962 by sociologist David Mechanic to refer to the way in which individuals may differently perceive, evaluate and react to their symptoms. By broadening this concept to one's own general health status, Pilowski underlies that there may be illness behaviour also in the absence of symptoms. In particular, illness behaviour turns into abnormal in those cases where patients present physical complaints "for which no adequate cause can be found" (Pilowski, 1969: 347. Quoted in Baszanger, 1998: 90), where, clearly, the adequate cause is an organic one. Pilowski claims that in some chronic pain sufferers' the patient's pain is "a form of illness behaviour that is chronic and abnormal." (Ibidem)

Abnormal illness behaviour (AIB) is defined by Pilowsky as

the persistence of an inappropriate or maladaptive mode of experiencing, evaluating and acting in relation to one's own health status, despite the fact that a doctor (or other appropriate social agent) has offered an accurate and lucid explanation of the nature of person's health status and an appropriate course of management. (Ibidem)

In the author's view, in some chronic pain patients the presence of an AIB is manifested by the fact that, despite the reassurances and the explanations of the physician, the patient continues to relate inappropriately to her pain. (Pilowski, 1990: 301) In the author's presentation, AIB is not a psychiatric condition in itself, but a form of deviant behaviour caused by psychological issues. Persistent pain may be an

AIB due to the presence of: i) a neurotic disorder, ii) a somatization disorder, iii) a conversion disorder in which pain is a conversion reaction, iv) Somatoform Pain Disorder, as classified in the DSM-III-R and v) Hypochondriasis.

Even though the concept of AIB refers to those chronic pain conditions having a psychiatric aetiology, the idea that prolonged pain may be a maladaptive approach of the patient to her condition (echoing Fordyce's framework) became a very influential framework to explain some problematic painful conditions and has not been abandoned yet in approaching persistent pain conditions in general.<sup>61</sup> As I will insist on in the next chapter on fibromyalgic syndrome, the idea that in chronic pain conditions the problem is not pain itself but the way in which the patient relates to it, is still a valid one, even though interpreted in several ways.

The concept of AIB has become a paradigm to explain the discrepancies between the patient's pain report and organic findings. This issue is particularly relevant in relation to the disability claims which, in an healthcare system such as US one, and, increasingly also in Europe, is a crucial matter. The debate on how to give credit to the patient's report to be in pain when physical findings lack has played a noteworthy role in the constitution of chronic pain as a disease. Conceptions such as that of AIB and that of Chronic Pain Syndrome, which will be later discussed, appear to be strongly related to the socio-economical context in which they have arisen, the US one, where the assessment of the presence of chronic pain in disability claimants is a remarkable issue. Focusing on this issue is therefore crucial, both to understand the

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<sup>61</sup> This concept is still employed in the definition of chronic pain. See Turk, Okifuji, 2000: 17

constitution of chronic pain as a disease and to unravel the relationships that disease' definitions have with the context in which they emerge.

One of the most extreme examples of a debatable approach aimed at evaluating the presence of pain in chronic sufferers is the methodology proposed in 1979 by physician Gordon Waddell, indicating how to reveal that the patient's pain is not organic. In a 1979 paper in *Spine*, Waddell describes a series of physical signs (today known as Waddell signs) indicating the presence of a non-organic aetiology of pain in low back patients' pain. In the article, Waddell presents five criteria to assess the "organicity" of the patient's pain. The findings are seen as clinically significant when at least three of these are discovered through the application of diagnostic techniques. First of all, the physician has to evaluate the tenderness, which in organic diseases is usually "localized to a particular skeletal or neuromuscular structure. Nonorganic tenderness is usually superficial or non-anatomic." (Waddell, 1979: 118) The second test is the simulation one, which "gives the patient the impression that a particular examination is carried on when in fact it is not." (Ibidem) Usually it is a movement that causes pain, which is not actually performed but only simulated: if the patient reports pain, a nonorganic process is supposed to underlie pain. Third, the distraction test, which is aimed at checking the presence of a pain previously claimed by the patient by distracting her and observing if even in this situation she claims to feel pain. Fourth, the regional disturbance: if a regional weakness or sensory change diverges from the accepted neuroanatomy, this may prove the presence of a nonorganic condition accounting for the pain. The last

technique is the assessment of the patient's overreaction to the clinical examination, which again is conceived of as an indicator of a nonorganic pathology.

The employment of Waddell's technique in the clinical practice has been debated mainly because its aim is not clear and also because although Waddell's signs may detect a non-organic component of pain, they do not exclude the presence of an organic pathology as well. Even if the presence of Waddell's signs is not considered as a proof of patient's deception in order to obtain a financial gain, Waddell's examination seems to have this purpose. In the US, chronic low back pain disability claimants represent an unsolved problem both for SSA and for insurance companies; Waddell's examination proposal seems to be aimed more at unmasking malingerers than at evaluating the presence of a chronic pain condition by helping to identify "patients who require more detailed psychological assessment."<sup>62</sup>

In 2003, Fishbain et al. discuss the value of Waddell's signs and the several interpretations given to these findings in the clinical practice, from malingering to AIB. From a review of the scientific literature available, Fishbain et al. conclude: i) these signs are not correlated with psychological distress and not even with secondary gain, ii) they do not discriminate organic from non-organic problems and may also represent an organic phenomenon; iii) Waddell's signs are associated instead with poorer treatment outcome, and with greater pain levels. The general conclusion is that Waddell's signs technique has inherent methodological problems and, therefore, it is not a reliable tool to assess the presence of a non-organic aetiology accounting

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<sup>62</sup> Waddell, 1979: 117

for the patient's pain. Beside the actual employment of this tool in the clinical practice, which, to my knowledge, has not been particularly successful, still Waddell signs' formulation witnesses for the relevance of the distinction between organic and psychological pain conditions; as it will be discussed in the next section, this question is deeply bounded to the recognition of disability to pain sufferers.

### *3.1.8 Chronic pain, abnormal illness behaviour and disability*

In 1980, US Social Security Administration (SSA) introduces several sections of its regulation concerning disability. Here, pain is included as a symptom to be evaluated in the determination of disability: pain can lead to the assessment of the disability when a medical condition that can be expected to produce pain is found.

In that period, strong controversies rise in the US concerning claimants disability requests due to somatic complaints -and in particular pain- not adequately accounted for by medical evidence of disease or injury. Moreover, tensions between the US SSA and federal courts in judgments concerning benefits because it often happened that administrative law judges and federal courts awarded benefits to claimants previously denied from SSA. Consequently, some amendments to the Social Security Act (P.L. 98-460) are introduced, including also the "first statutory standard defining how pain should be evaluated for purposes of determining eligibility for disability benefits." (IOM Committee on Pain, Disability, and Chronic Illness Behavior, 1987, v)

This law indicates that

an individual's statement as to pain (...) shall not alone be conclusive evidence of disability (...) there must be medical signs and findings which show the existence of a medical impairment that results from anatomical, physiological, or psychological abnormalities



which could reasonably be expected to produce the pain (...) and which (...) would lead to the conclusion that the individual is under a disability<sup>63</sup>

As a part of this legislation, a Commission for the Evaluation of Pain is constituted on request of the Congress, with the main purpose to study the pain evaluation policy and recommend changes if appropriate. This Commission is asked to work in consultation with the National Academy of Science and the Institute of Medicine (IOM) is appointed for this task.

In IOM's report, the employment of concept of illness behavior<sup>64</sup> in relation to chronic disabling pain disproportionate to clinical findings is noteworthy, as a consequence of the explicit request of the SSA to “describe how the concept of illness behavior provides a framework for understanding the observed discrepancies between the clinical manifestation of pain and the behaviors of people with pain.” (IOM, 1987: 146) In the conclusions, the Committee recommends to include neither “illness behaviour” nor “chronic pain syndrome” in the list of impairments that allow a presumption of disability because these notions do not refer to diseases or diagnoses. Illness behavior, it is claimed, has an heuristic value and should facilitate administrative inquiry for benefits. “Chronic pain syndrome”, as well as illness behavior concept, fails to meet the criteria of medical conditions because of the lack of “demonstration of a common etiology, a predictable natural history, a clearly defined constellation of symptoms, or a specific treatment for the various pain

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<sup>63</sup> Section 3(a) of P.L. 98-460, Social Security Disability Benefits Reform Act of 1984, quoted in IOM, 1987, 52. This is also the first time a standard for evaluating pain is codified in a law

<sup>64</sup> It may be relevant to remark that one of the members of the Commission was Professor Mechanic, who also proposed first this notion

conditions that would suggest a basis for positing a single chronic pain syndrome.” (IOM Committee on Pain, Disability, and Chronic Illness Behavior, 1987: 8)

The notion of “chronic pain syndrome”, which recalls Fordyce's conception of maladaptive behavior noticeable in some chronic pain sufferers, has given way to a strong debate inside pain medicine.

### *3.1.9 A controversial approach to chronic pain: the chronic pain syndrome*

In 1975, psychiatrist Richard G. Black suggests reserving the definition “chronic pain syndrome” for patients who complain of persistent pain often not accounted for by physical problems or diseases, attempting to make a strong distinction between a psychological and physiological aetiology at the basis of the patient's pain behaviour. Bonica and other IASP members reject this approach, claiming that it fundamentally misunderstands the complexity of chronic pain conditions (See Baszanger, 1998: 90-91). Eventually, the IASP textbook *Classification of Chronic Pain Syndromes* groups all existing chronic pain conditions together: nociceptive, neuropathic, long-term disease-related, non life-threatening and psychogenic pain. Nonetheless, controversies remain: the authors claim in the Introduction that “it is common in North America to find that patients are described as having Chronic Pain Syndrome” (IASP, 1994: xiii) who are diagnosed when there is “a persisting pattern of pain that may have arisen from organic cause but which is now compounded by psychological and social problems in behavioural changes.” (Ibidem) In this case, the IASP Subcommittee on Taxonomy deems it better to make both physical and psychiatric diagnosis and to indicate the contribution of each diagnosis to the patient's condition.

The definition of Chronic Pain Syndrome is discarded by the IASP because, even if it is recognized that experientially pain is a unitary phenomenon, it is still necessary to identify psychological and physiological contributions and also because “it was noted that the term CPS is often, unfortunately, used pejoratively” (Ibidem).

Chronic Pain Syndrome -whose diagnostic traits recall those of DSM Pain Disorder- has been defined as a psychosocial disorder in which somatic preoccupation consumes the patient's attention, leading her to pursue a maladaptive behaviour that may be incapacitating (NPC, 2001: 11-12).

This disease conception focuses on the patient's reaction to the painful condition and regards the sufferer's behaviour as the main issue in chronic pain disease. Baszanger argues that debated classifications, such as Black's “chronic pain syndrome”, are due to the presence inside pain medicine of two main ways of conceiving of chronic pain which have characterized the constitution of this entity as a disease; a first one focusing mainly on pain itself, and a second which considers instead the patient's behavior as the main focus of this condition. In Baszanger's view, these approaches nowadays coexist inside pain medicine and the pluridisciplinary nature of Bonica's pain clinic supports this situation. This leads Baszanger to the conclusion that there is no such a thing as a unitary model of chronic pain, but more than one model, and that “all practical forms of implementation of a pain clinic or pain center are compromises, arrangements 'strung out' between these two theoretical models.” (Baszanger, 1998: 95) Chronic pain seems therefore to be the product of the different ways in which this condition is

actually handled in the practice and a definition that goes beyond that seems to be unattainable. The influence of the medical context in which chronic pain conditions are actually handled is definitely a pivotal issue in relation to the definition of persistent pain as a pathological condition. The analysis of fibromyalgic syndrome presented in the next chapter will precisely deal with this topic.

In the third edition of Bonica's textbook, Jacobson and Mariano claim that "chronic pain syndrome" term is often employed even if it is not officially recognized. As previously claimed, "chronic pain syndrome" does not represent a valid nosological categorization and it seems more to be a rag-bag category collecting an heterogeneity of chronic pain conditions which "do not present with a coherent, clearly defined constellation of symptoms and signs that denote a medical diagnosis." (Ibidem) The authors propose to substitute this term with "overwhelming' chronic pain syndrome" which, in their view, is more useful in describing those conditions in which both the patient as well as the physician are overwhelmed: the patient by her pain and the physician and the disability system, by the patient. According to the authors, the core feature of these patients is the fact that they "repeatedly present to biomedical providers with pervasive disability and severe emotional distress that they attribute to pains that do not respond to conventional treatments." (Ibidem) Even if this definition of the condition does not differ much from the previously mentioned description of "chronic pain syndrome", it is clear that the scope of the authors transcends a mere terminological concern, and aims at indicating that this condition has to be completely reviewed from another perspective. As the authors claim, this

entity is not a medical condition characterized by psychopathological features but a “psychosocial problem that is all too often managed in a biomedical culture and setting.” (Ibidem) This conception appears to be directly connected to a broader element which the authors see as characterizing the relationship between chronic pain and biomedicine, i.e. that of *demedicalization* of these conditions. As the authors maintain,

demedicalization is a process of challenging the belief that pain is the patient’s primary problem and that medical interventions are the only solution. The full range of medical interventions are used but in a context that emphasises the far greater importance of the efforts the patient makes in his or her own rehabilitation. (Jacobson, Mariano, 2001: 248)

#### *3.1.10 Conclusion*

On a strictly pragmatic perspective, the absence of an ultimate and shared definition of chronic pain as a disease may appear not troublesome: the multidimensional shape of the phenomenon justifies the presence of a plurality of conceptions as well as of therapeutic approaches so that, in the end, what is relevant is whether the conception underlying a specific treatment to the condition is useful or not. Nevertheless, as I have shown in this section, the lack of a definition of the phenomenon, in particular when the prolonged pain is not accounted for by a detectable organic damage, may lead to the doubt that the persistence of pain the pain is caused by psychopathological issues. This presumption may entail several consequences: first of all, as showed in the previous chapter, the categorization of pain as “psychogenic” is highly problematic. Moreover, as I will point out in the next section, considering a pain as psychogenic entails somehow conceiving of it as “less

real” than an organic one. This, in turn, may lead to a stigmatization of the sufferers, whose conditions’ “reality”, or, at least, their severity, turn out being somehow doubted. Second, on a clinical perspective, labelling a pain as psychogenic has noteworthy consequences on the choice of the proper treatment of the patients. As I will discuss in the last chapter of the dissertation, the integrated approach to chronic pain grounded on the collaboration of different specialists is often more an ideal than a reality. Consequently, the definition of the condition, e.g. as a mental disorder, is strongly influenced by the context in which it is handled and, even though antidepressants are widely employed also in the treatment of chronic pain conditions, the implications of this prescription remains to be tackled. Third and finally, no matter the recurring claims that all pains are real, the issue of the “organicity” of pain is crucial for the patients in disability insurance benefits’ claims. In this regard, how a condition such as “overwhelming chronic pain syndrome” would be considered?

In a 1991 paper, neurologist John D. Loeser discusses the relationships between chronic pain conditions of unknown aetiology, individual impairment and disability. Chronic low back pain is an exemplary problematic chronic pain condition in this regard. Loeser remarks that in less than 15% of these patients a diagnosis is established; this lack of recognition of the mechanisms underlying pain may lead these patients to get multiple diagnoses depending on the different specialists’ area, as well as disparate treatment strategies which often are minimally effective. Moreover, the blurred status of the morbid process underlying these conditions may entail the fact that patients receive a certification of disability before having the

chance to follow rehabilitative programs. Loeser attributes the responsibility for this troublesome situation to the workmen's compensation systems, which often are more willing to pay for acute interventions than for pain management or rehabilitative programs. Workmen's Compensation system fails in dealing with conditions such as back pain one mainly because its decisions are grounded on the acknowledgement of the presence of a tissue damage made by a physician to account for the presence of an impairment. The World Health Organization (WHO) defines "impairment" as "any loss or abnormality of psychological, physiological, or anatomical structure of function."<sup>65</sup>; "disability" is defined instead as "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for the human being." (Ibidem) In chronic pain conditions of unknown aetiology, these assessments are very difficult to make because the supposed relationship postulated by the WHO between impairment and disability lacks "as the chronic pain patient may have no measurable impairment that underlies disability due to pain." (Loeser, 1991: 217) Therefore, Loeser concludes that "it is time to change the method of assessing and rewarding disability due to chronic pain" (Ibidem) and also to stop funding treatment programs that do not affect behavioural change which in his view is a prominent aspect of these conditions. The matter of the

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<sup>65</sup> WHO, 1980. Quoted in Loeser, 1991: 217. WHO's definitions of "impairment" and "disability" have been rielaborated in 2001 in what is known as the International Classification of Functioning. The definitions have been rielaborated in order to integrate social and biomedical models of disability. These changes haven't affected anyway the issues rised by Loeser in relation to elusive chronic pain conditions

recognition of the disability for chronic pain sufferers will be discussed with reference to fibromyalgic patients' situation in the Italian context in the forthcoming chapter.

In the present section, I have attempted to sketch a scenario of the several issues which have shaped the definition of chronic pain as a disease. Among these, the different theoretical frameworks in which chronic pain has been interpreted and defined in the history are deeply intertwined with socio-economical issues particularly relevant in a context such as the US one where pain medicine has risen, but which represent today pivotal questions also in Europe. From this analyses, it appears that the definition of pain as a disease in knowledge is strongly affected by issues which transcend strictly epistemological matters.

In the following section, I will further discuss chronic pain by analyzing its classification in the International Disease Classification (ICD), last edition (ICD-10) by the WHO. After showing the problematic status of chronic pain in disease classification, I will present a philosophical analysis of what I see as the main reason of the troublesome acknowledgment of chronic pain as disease, i.e. an aetiological dualism characterizing biomedical approach to pain. I will further discuss such a dualism by arguing that the dichotomic framework in which biomedicine acts is no more the supposed Cartesian dualism between mind and body, but that other forms of dualism are noticeable in biomedical approach to chronic pain.

### *3.2 Chronic pain as a disease*

#### *3.2.1 Introduction*



In this section I will focus on the problematical status of chronic pain as a disease entity. First, I will look at the classification of chronic pain in the last edition of the International Classification of Diseases (ICD-10) and I will discuss some disputable issues that this categorization of chronic pain presents.

I will then discuss the main troublesome issues related to the acknowledgement of the disease status of chronic pain in biomedicine, focusing in particular on the issue of the problematic aetiology of chronic pain. This situation leads to a “scientific uncertainty” about the nature of chronic pain in itself which, in conjunction with a particular type of dualism of the biomedical disease model, may lead to a stigmatization of chronic pain patients.

### *3.2.2 Chronic pain in disease classifications*

The ICD is WHO's “international standard diagnostic classification for all general epidemiological and many health management purposes.” (ICD-10, 1994, 2: 3) As stated in the manual's Introduction, the aim of the ICD is to present a classification of diseases intended as “a system of categories to which morbid entities are assigned according to established criteria (...) ICD is used to translate diagnoses of diseases and other health problems from words into an alphanumeric code, which permits easy storage, retrieval and analyses of data.” (Ibidem)

In ICD-10, a variety of pains and painful symptoms are presented, each one related to a particular location of the pain. There is a specific cluster for *Chronic Intractable Pain*. This classification falls under the category “Pain, not elsewhere classified” (R52) in the chapter XVIII “Symptoms, signs and abnormal clinical and

laboratory findings, not elsewhere classified”. In this section of the manual are collected

the less well-defined conditions and symptoms that, without the necessary study of the case to establish a final diagnosis, point perhaps equally to two or more diseases or to two or more systems of the body. Practically all categories in the chapter could be designated “not otherwise specified”, “unknown etiology” or “transient” (WHO, 1994, I: 823)

“Pain, not elsewhere classified” (R52) includes those pains “not referable to any one organ or body region” and is specified in four different subtypes: *Acute Pain* (R52.0), *Chronic Intractable Pain* (R52.1), *Other Chronic Pain* (R52.2) and *Unspecified Pain* (R52.9).

The definition of pain as treatment resistant recalls the first definition given in 1953 by Bonica of those abnormal pains which were the primary focus of pain medicine's attention. Nevertheless, at that time the employment of this notion was due to the lack of a classification for chronic pain. Moreover, in Bonica's abnormal pains' cluster different types of pain were collected whose underlying mechanisms were not clear yet, such as those caused by a dysfunction of the central nervous system, as well as those chronic pains with unknown aetiology. Nowadays, chronic pain is indeed formally recognized as a pathological entity and there is also a specific classification for chronic pain syndromes put forward by the IASP in 1986, with a second edition in 1994. In the Introduction of the 2<sup>nd</sup> edition of chronic pain syndromes' classification, the authors claim that the aim of the work is to constitute a useful tool for medical practice, in particular to facilitate the communication between different clinicians

dealing with chronic painful conditions. IASP's classification of chronic pain is built around five main axes which classify pain on the basis of i) the body regions where the pain is felt, ii) the systems involved in the production of pain, iii) the temporal characteristics of pain, iv) the patient's statement of pain intensity and, finally, v) pain aetiology. It may be remarkable in relation to the discussion on "psychogenic pain" that the tenth code of pain aetiology's digit is "psychological hysteria" (e.g. conversion hysteria, depressive hallucination); this subtype is accompanied by the note: "No physical cause should be held to be present, nor any psychopathological mechanism."<sup>66</sup> "Psychogenic pain" is therefore still present in IASP's classification of pain and described as a pure psychopathological disorder belonging to hysteria's family of disorders.

Even if IASP's classification of chronic pain syndromes represents a shared categorization of chronic pain conditions, this does not justify the huge gap of classification of chronic pain in the ICD. *Chronic Intractable Pain* results difficult to be interpreted and, without any further specification, clearly this categorization is not a valid disease classification. At the same time, it is important to remark that ICD classification of diseases, unlike the DSM, has not diagnostic purposes but it is aimed at collecting all existing morbid conditions. In the description of the ICD, it is claimed that the structure of the manual is based on the grouping of statistical data as describing epidemic diseases, constitutional or general diseases, local diseases arranged by site, developmental diseases and injuries. In this perspective, *Chronic*

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<sup>66</sup> Merskey, 1983: 45. Quoted in Baszanger, 1998: 88

*Intractable Pain's* lack of criteria defining the condition seems to be somehow justified. Nevertheless, one may wonder what kind of condition those patients were suffering for when the healthcare professionals have diagnosed them as having *Chronic Intractable Pain*. More specifically, did these patients represent an homogeneous category? And if this is the case (even if this hypothesis seems highly improbable), what do these patients share beside the fact that the persistent pain they are suffering for is not treatable?

In any case, the problematic status of chronic pain classification in the ICD-10 is noticeable when looking at the classification of “psychogenic pain” in the manual. “Pain, not elsewhere classified” category excludes indeed those pains localized in a specific body part or region such as headache and also chronic pain syndrome and psychogenic pain. *Chronic pain personality syndrome* (F62.8) is part of the “Enduring personality changes, non attributable to brain damage and disease” category (F62) in the section collecting mental and behavioural disorders. (WHO, 1994,1: 341) Here, it is also classified “psychogenic pain” as *Persistent Somatoform Pain Disorder* (F45.4) where

the predominant complaint is of persistent, severe and distressing pain, which cannot be explained fully by a physiological process or a physical disorder, and which occurs in association with emotional conflict or psychosocial problems that are sufficient to allow the conclusion that they are the main causative influences.<sup>67</sup>

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<sup>67</sup> WHO, Persistent Somatoform Pain Disorder (F45.4). Accessed September 6, 2011: <http://apps.who.int/classifications/apps/icd/icd10online/>

This category includes the so-called psychalgia (a synonym of psychogenic pain), psychogenic backache, headache and somatoform pain disorder.

The criteria defining ICD's *Persistent somatoform pain disorder* category overlap with DSM-IV *Pain Disorder* -psychological type- one. The only difference is the fact that the ICD category seems to focus only on persistent pains, while in the DSM the diagnostician can make this diagnosis and then specify if the pain is acute or chronic. Nevertheless, it is not clear if the difference between ICD and DSM classification is actually relevant: *Persistent Somatoform Pain Disorder* includes indeed also “somatoform pain disorder”, which is DSM-III classification of “psychogenic pain”, that in the DSM-IV will become *Pain Disorder*. Moreover, in the ICD-10 last revised edition (2012), *Persistent Somatoform Disorder* becomes “Pain disorders exclusively related to psychological factors” which can be associated to acute or chronic pain. ICD-10 classification of “psychogenic pain” follows therefore DSM categorization without any particular revision. Moreover, ICD-10 “Persistent somatoform pain disorder” seems to share the same problematic issues with DSM-IV *Pain Disorder*, so that one may wonder on the basis of which criteria a diagnostician is supposed to assess that the untreatable chronic pain condition is accounted for by psychopathological factors.

From this review, the status of chronic pain as a disease seems to be problematic in ICD classification. Even if *Chronic Intractable Pain* and other chronic pains are excluded from “Persistent somatoform pain disorder” category (the psychiatric classification of pain in ICD-10), if the pain is not localized in a particular body area, it

turns out to be somehow unclassifiable. The categorisation “Pain, not elsewhere classified” is a cluster for unexplained pains<sup>68</sup>: what the pains collected here share is the fact that they don't fit in any other category because of the lack of a criterion, a precise location. The cluster “Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified” is meant in fact to collect all those entities which are reasons for which a person may contact health services, but that cannot be categorized following the framework of ICD's diagnoses. Chronic pain not related to a precise location of the body does not find a place in ICD classification and the presence of “Chronic intractable pain” classification results ambiguous. Furthermore, ICD does not present a categorization of chronic pain with unequivocal features and clear boundaries. Hence, with ICD classification of chronic pain we get landed with a classification of chronic pain with a psychological aetiology along the lines of DSM's one and a category for chronic pain mainly defined by the fact that these pains are hardly classifiable as “normal” pains because they are untreatable. Hence, it seems very difficult to distinguish on the basis of this classification between those pains which persist for unexplained reasons and those which persist because of the presence of a psychopathological mechanism underlying pain, or maybe because the patient has developed an AIB. The doubt on the reasons of the resistance of pain to treatment in conjunction with a problematic classification of “psychogenic” persistent pains in the ICD recalls the already mentioned issue of the difficulty to acknowledge

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<sup>68</sup> As highlighted in the previous chapter, a categorization grounded on the exclusion of other conditions is defining DSM-IV *Pain Disorder* too

chronic pain as a complex entity characterized by psychological as well as physiological features.

### *3.3.3 The problematic status of chronic pain as a disease*

In a 1996 paper on chronic pain as a disease, neurologist and pain expert John D. Loeser<sup>69</sup> highlights, that in his first analyses Bonica assumed that “every pain had a cause that was as tangible as any other aspect of disease process.” (Loeser, 1996: 101) The physician was supposed therefore to “uncover this cause by history, physical examination, laboratory tests” (Ibidem) and, by finding the cause, pain itself could be eliminated either by treating the underlying disease or by acting directly on the pain itself. According to Loeser, this approach was the legacy of a Cartesian dualism -seeing of pain as the psychological manifestation of an organic damage- inherent to the biomedical disease model which has proven to be unsuccessful in dealing with pain. Loeser argues that what distinguishes pain from other morbid conditions such as a tuberculosis is the fact that while the diagnosis of tuberculosis is made on the basis of findings such as the presence of bacilli, with pain it is different. Loeser concludes: “proving the existence of an abstract concept such as pain is altogether another matter.” (Ibidem) Paraphrasing Loeser, the main troublesome issue for the physician dealing with chronic pain is the fact that the presence of pain, unlike other diseases, cannot be proven. This is why physicians find themselves without resources to make a diagnosis since usually the diagnostic process is grounded on the presence of detectable findings pointing to a morbid condition. With

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<sup>69</sup> John D. Loeser has edited also 3<sup>rd</sup> edition of Bonica's manual

pain, the author argues, this process is not pursuable, because pain is an abstract concept.

Even if Loeser's reasoning is almost completely shareable, his conclusion does not seem to be coherent. First, the definition of pain as "an abstract concept" is objectionable. Being indulgent with the author, one may interpret this definition as aimed at stressing that pain is a psychological state and, following Loeser's thesis, that what is troublesome in approaching pain as a disease is that pain is not underlied by the same type of causal relationship linking tuberculosis to bacilli. One may reply, though, that this type of relationship is often not available for the majority of the diseases and this is also why currently medicine prefers to employ wide multicausal models. The difference of chronic pain from other morbid conditions appears to be due to the epistemic status of pain knowledge which, as it has been previously remarked, is accorded to the sufferer. Such a peculiar status of pain may lead to an "uncertainty" on chronic pain status when confronted with a disease model conceiving of disease as a morbid entity intimately linked to its cause in a linear and straightforward causal relationship. Chronic pain, instead, is usually initially triggered by an injury or a disease but, as the definition states, nociceptive impulses persist after healing, often without a known cause. This fact, in association with the frequent comorbidity of chronic pain with psychiatric conditions, may introduce doubts in relation to the role played by psychopathological factors in pain onset and maintenance, i.e. is the pain or its persistence due to psychopathological issues?



I argue that one of the main problematic issues in conceiving of chronic pain as a disease entity is related to this “uncertainty” stressed by Loeser, that is so problematic for biomedicine because it concerns the aetiology. Roughly speaking, if the pain is accounted for by the detection of a damage (that can be peripheral or as in neuropathic pains affecting the nervous system), the presence of pain is accepted because it is clear which is the underlying mechanism producing it. The fact that the patient is in pain, therefore, is not questionable. Chronic pain, instead, and above all the so-called chronic pain without lesion, scarcely fits into this traditional model mainly because of the lack of scientific certainty about its aetiology and about the mechanisms underlying its persistence; this, in addition to the fact that persistent pain is often accompanied by mood problems and to the impossibility to assess objectively the presence of pain, leads to the doubt on the organic nature of the pain. Moreover, the stress on pain aetiology often appears to be grounded on a fundamental dualism in conceiving of mind and body. In dismissing the inherent complexity of chronic pain conditions, this approach entails a conception of chronic pain (and pain in itself) as accountable either by a mental aetiological explanation or by an organic one. Hence, although chronic pain’s disease status has been formally and scientifically recognized, this acknowledgment remains partial and sometimes ambiguous. The reason for the blurred status of chronic pain as a disease is mainly due to a clash between different sources of knowledge: on the one hand, from a scientific perspective, chronic pain is a disease because of clearly observable and measurable features like the changes in physiological response patterns,

psychological and behavioural features characterizing it as a pathological phenomenon. On the other hand, as I have argued, chronic pain disease status is challenged by the difficulty to deal with the multifaceted character of pain in itself and, especially in chronic pain conditions with a problematic aetiology, by the narrowness of the medical disease model. In this regard, it is relevant to remark that different conceptions of chronic pain as a disease emerge by looking at medical literature on chronic pain and by referring instead to the clinical approach to chronic pain. The latter will be further discussed in the next chapter in which I will specifically focus on clinical approach to fibromyalgic syndrome.

#### *3.3.4 Chronic pain and dualism: which dualism?*

As in Loeser's argument, in medical debates it is very common to notice the allegation to pursue approaches to disease grounded on Cartesian dualism<sup>70</sup>, in particular in relation to painful conditions<sup>71</sup>. Nevertheless, this discourse often seems to be more a rhetorical one aimed at claiming that the human being has to be conceived -and treated- in her complexity, rather than a critique addressed to approaches actually grounded on Cartesian dualism. Nowadays, indeed, there are few physicians committed to such an approach and unaware of the powerful

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<sup>70</sup> In the Introduction of the DSM-IV, the authors claim not to be happy with the notion of "mental disorder" because it entails a distinction between mental and physical conditions that is a reductionist anachronism inspired by mind/body dualism; nevertheless, they say that they could not do otherwise because an appropriate substitute has not been found

<sup>71</sup> In pain medicine's debates this allegation has been made quite often. See, for example, Wall, 1985: 73 quoted in Jackson, 2005: 335: "[Pain is] a Cartesian dualism by its subdivision (..) into 'sensory' and 'psychological'. This is an intellectual artifice invented to preserve a concept of divided brain and mind". See also Jacobson and Mariano, 2001: 245. Quoted in Loeser: 2001

relationships between mind and body in disease; moreover, most psychiatrists have physicalist conceptions of mind and brain. Hence, even though in biomedicine the allegation of a dualistic approach to the patient seems to be still a valid one, it is no longer to be seen in its supposed Cartesian version<sup>72</sup>, i.e. the split of the person in two different entities, a transcendent nonmaterial mind and a material body with a mechanical functioning<sup>73</sup>. As Sullivan remarks, this version of biomedical dualism has been overcome by another form of dualism which entails a “disparity between what patients require and what medicine delivers” (Sullivan, 1986: 332), that is the dualism between disease and illness. In this perspective, biomedicine tends to focus solely on the disease seen as dysfunctions or abnormalities in the body, and dismisses illness, the lived experience of the patient of a “disvalued change in states of being and social function” (Eisenberg, 1977. Quoted in Sullivan, 1987: 332) According to the author, this dualism originates not in Cartesian dualism, but in an epistemological dualism, mainly derived from Bichat's anatomopatological method. Bichat's model sees a total coincidence between the tissue lesion and the disease (See Sullivan, 1987: 339-339 and Foucault, 1973); this entails that diseases are conceived of as identical to their symptoms and, definitively, after the autopsy, as coincident with the lesions detectable in the patient's dead body. Therefore, Sullivan maintains, “the lesion becomes the necessary and sufficient condition for the presence of

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<sup>72</sup> In a 2000 paper, Duncan argues that the allegation to Descartes, that of having postulated the separation between psyche and soma is misleading. In Duncan's view, Descartes mental philosophy, in particular his analyses of pain was meant to explain the union of psyche and soma

<sup>73</sup> See Sullivan, 1986

disease. By revealing the lesion at autopsy, it becomes possible for the physician to identify disease in a way totally independent of the patient's experience of it." (Sullivan, 1987: 335) The possibility to make the disease autonomous from the patient's experience of it, which becomes only "an object among others to be known" (Sullivan, 1987: 337), allows a "non- arbitrary" knowledge which, as Sullivan argues, is the ultimate scope of both Bichat's and Descartes' method. The biomedical dualism rising from such a conception of disease, Sullivan concludes, is therefore an epistemological one, grounded on an overwhelming gap not between two different substances, mind and body (Descartes), but between the physician as an active knower and the patient as a passive known object.

Sullivan's poignant thesis appears particularly fruitful in the analyses of chronic pain as a disease. Pain subjectivity, as it has been previously highlighted, does not allow the type of knowledge grounded on a distinction between disease and the diseased subject. The subjectivity of pain entails indeed two main issues: first of all, pain is always a psychological state and therefore it is dependent on several individual variables which make it unintelligible for any other subject but the individual who is actually experiencing it, and, consequently, the knowledge of pain cannot be achieved without referring to the sufferer. Moreover, as Foucault has eminently claimed, Bichat's anatomopathological method finds its validity in the evidence of a correlation between pathology and anatomical lesion in the autopsy, when the physician opens up the corpse and finds the ultimate proof of the disease. Persistent pain, as other chronic conditions, makes this unattainable: this is one of the major

challenges that chronicity poses to biomedicine, i.e. the need to approach and deal with the diseased individual in her daily living with the pathology and not with the disease as an inert object.

In a 1988 work, anthropologist Kirmayer draws on Sullivan's thesis by claiming that the mind-body problem is no more an issue for biomedicine, at least in its supposed Cartesian formulation. The relationship (and the conflict) between mind and body remains though a problem for biomedicine in an ethical perspective. According to the author, contemporary biomedical mind-body dualism is grounded on a metaphorical conception of these entities: mind and body symbolize "contrasting poles in human experience: the voluntary or intentional and the involuntary or accidental." (Kirmayer, 1988: 57) The persistence of the dualism is therefore related to moral and social issues because "the contrast between wilful action and impersonal accident is central to both the private sense of self and the public concept of the person" (Ibidem), which are core issues in events such as sickness and disability. This dualism, Kirmayer argues, is not originated in Western biomedicine which, however reinforces it in its approach to irrationality and sickness, grounded on the dominant metaphor of the body as a machine. In this framework, when the body-machine has a problem, the patient demands to the physician to repair it and, in this way, she adopts the sick-role by adhering to the therapeutic indications offered by the physician. If the patient does not follow the physicians' indications or the healing is not accomplished, the patient may be blamed for her failure. If the physician feels that he or she has done everything in his or her power in order to fix the problem but

still the patient complains about pain, the conclusion may be that that pain has to be caused by psychological issues. Problematic and unexplained conditions in which the patient's claim of suffering is not accounted for by an organic damage are exemplar in this regard. Moreover, Kirmayer shows how also the psychosomatic approach, e.g. the biopsychosocial model (See Engel, 1977) which is usually presented as a solution to the narrowness of biomedical approach, is characterized by the same rationalistic values of biomedicine. Even if the scope of psychosomatic approaches is considering mind and body as parts of the same continuum, often this aim is indicated as reachable through the "reestablishment of the mind's dominance and control over the body and, with it, of reason over emotion." (Kirmayer, 1988: 58) Again, therefore, when the healing is not accomplished, psychosomatic explanations, such as the stress one, always involve at least a partial responsibility of the patient for their condition. This, Kirmayer claims, entails a doubt on the reality of the patient's disease since that "'real' sickness in Western culture is an exemplar of the kind of misfortune that just happen to us. Consequently, wherever responsibility is imputed, a person cannot be 'really' sick until an autonomous (biological) process takes hold." (Kirmayer, 1988: 75) Hence, people suffering from problematic conditions which cannot be accounted for by an organic (physical) explanation, such as the so-called chronic pain without lesion, are seen as "either rational but morally suspect in choosing to be sick, or irrational and thus morally blameless but mentally incompetent." (Kirmayer, 1998:83)

The persistence in biomedicine of a dualistic framework in approaching diseases represents a thrilling and crucial topic to discuss in relation to the acknowledgment of chronic pain as a disease. Nevertheless, as I am trying to show by referring to the fundamental analyses of scholars such as Sullivan and Kirmayer, the dualism inherent to biomedical model is more complex (and tricky) than what is seen as the Cartesian version of it. This may entail, as shown in the next chapter that, in the clinical practice the boundaries between mind and body and the contribution of them to chronic pain may be very blurred, and also that a dichotomic distinction between psychological and physiological approaches is not clear-cut or it is reinterpreted in the single practical contexts where the specific, individual conditions are dealt with.

In a 2005 work, anthropologist Jackson discusses the challenging status of chronic pain in biomedicine to the traditional boundaries between mind and body. Moreover, Jackson maintains, chronic pain patients themselves have a problematic status since that they are “neither properly well nor properly sick” (Jackson, 1995: 345) which may lead to a confusion of the codes surrounding sickness and health. The anthropologist argues that, for these reasons, chronic pain patients are in a position of liminality<sup>74</sup>, which may lead them to be stigmatized by physicians. The chronicity of persistent pain entails the fact that to chronic pain “is accorded less legitimacy than acute conditions, for, as Talcott Parsons (1958) points out, the sick role is legitimate only for a period of time.” (Jackson, 2005: 333)

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<sup>74</sup> Here Jackson employs the concept of “liminality” both in the sense of “betwixt and between” (Turner, 1969) and in the sense of “matter out of place” (Douglas, 1966)

Jackson indicates three main reasons leading to a delegitimation of chronic pain conditions: first, chronic pain challenges the traditional conception of pain as something that, at a certain point, ceases. In this sense, the unaccountability of persistent pain in biomedical framework entails a blurred status of these conditions in biomedicine. Second, “a kind of ‘mountain-out-of-a-molehill’ response” which may lead to blame people who keep on complaining about pain because they are seen as having exaggerated reaction. Finally, the delegitimation occurs when psychopathological factors are involved. Seeing of a pain as psychogenic, as Jackson argues (See Jackson, 1992), entails that the sufferer’s painful condition is seen as “less real” an organic one. Jackson remarks also on the challenging character of chronic pain for biomedicine mainly due to “the conflict between physiology and psychology” (Jackson, 1005: 336) which recalls the long-standing issue of the relationship between pain and the tissue damage. As Jackson reports, chronic is often seen as requiring the absence of a tissue damage, even if nobody in the medical literature takes an ultimate position on this matter.

From a review of scientific literature on chronic pain, psychologist Gamsa, who has analyzed this question at length, indicates that biomedical approaches to pain are usually grounded on the assumption that pain may be caused either by organic or psychological factors, but not both; this seems to be due to the persistence of dualistic conceptions and linear causal explanations of pain. Moreover, Gamsa claims that in the clinical practice “pain continues to be attributed to psychological causes when physical findings are lacking and pain persists despite medical



intervention.” (Gamsa, 1994: 23) The problem is that this conclusion is often made even if a psychological aetiology has not been demonstrated. Gamsa suggests that the tendency to split psyche from soma when dealing with pain may be due to the frustration of physicians who, no matter the efforts made to help the patients, still have not be able to solve the problem and often find also these patients to be hostile in their estimation of medics. Nevertheless, Gamsa concludes by arguing that “thoughtful separation of mind and body remains a legitimate conceptual convenience, facilitating the continued search for the multiple causes of pain.” (Gamsa, 1994, II, 24)

In conclusion, chronic pain sharply challenges the biomedical traditional model of disease and this is mainly due to its liminal status which transgresses multiple boundaries constituting biomedicine. In Jackson's perspective, chronic pain patients transgress in particular the boundaries between mind and body which may lead also to a confusion of morality codes surrounding sickness and health. Chronic pain patients embody this uncertain status of persistent pain and may therefore elicit stigmatizing reactions in others. Moreover, as Jackson claims, “although not all cases of liminality are perceived negatively (...) liminality is positively valued only when society provides a special status or role for the liminal object, state or being.” (Jackson, 2005: 333) Notwithstanding the efforts made to find this place for chronic pain in biomedicine, in the clinical practice chronic pain remains a troublesome object and part of this situation may be due to chronic pain liminal status in disease classifications. As I will argue in the next chapter by referring to fibromyalgic

syndrome, this situation is further worsened by the conjunction of the aetiological-dualistic model of disease with a lack of communication between different medical specialties.

By referring to these analyses, I see as particularly relevant in a clinical perspective the persistence of the biomedical approach which postulates an overwhelming gap between those chronic pain conditions seen as psychogenic, and therefore to a certain degree unreal, and those conditions with a detectable organic cause as therefore seems having a higher degree of reality. In this regard, the way in which the correlation between chronic pain and depression is interpreted is a controversial issue in contemporary approaches to chronic pain patients.

### *3.2.6 Chronic pain and depression: a digression*

Scientific literature indicates that chronic pain is often associated with high rates of depression. (See Katon, Sullivan, 1990; Fishbain et al, 1997; Wasan, Sullivan and Clark, 2001) The nature of this relationship has been debated at length, mainly as to whether depression should be conceived of as a cause or as a consequence of chronic pain. Even if today such univocal approaches are no longer considered valid, this issue remains pivotal for clinicians as well as for chronic pain sufferers.

In this section, I will briefly present the contemporary debate on scientific understanding of the relationship between chronic pain and depression. The relevance of this debate is fundamental both from an epistemological point of view and in relation to the clinical practice. In particular, the issue of the frequent comorbidity of chronic pain and depression is a challenging topic in relation to two

main issues, the treatment and the potential stigmatization of a diagnosis of depression.

*The biology of chronic pain and depression*

Biological theories accounting for the association between pain and depression have been put forward from the second half of the XX<sup>th</sup> century when the role of endogenous opioids in mediating the relationship between pain and depression is assessed. (See Merskey, 1965) In the Eighties, studies indicate the influence of biogenic amines (serotonin, norepinephrine and dopamine) in pain modulation.

Today it is well-known that depressed individuals have a higher sensitivity to noxious stimuli; these patients generally have a reduced pain threshold. Moreover, it is widely acknowledged that chronic pain and depression share similar neural structures. Four neuro-transmitters play a pivotal role in both depression and pain: serotonin, norepinephrine, the substance P and the corticotrophin-releasing factor (CRF). (See Campbell et al., 2003) The modulating action of serotonin and norepinephrine on the descending inhibitory system has similar regulatory effects on the mood. Serotonin-norepinephrine reuptake inhibitors (SNRIs) have shown to be effective on both depression and pain. The analgesic properties of these substances appear independent of their action on the mood. Duloxetine and Venlafaxine are two drugs belonging to this category which have been approved by the Food and Drugs Administration (FDA) in the treatment of some chronic pain conditions; it has been showed that the analgesic properties of these substances are independent by their action on the mood.

At any rate, from a biological perspective there is a remarkable heterogeneity in the relationship between depression and chronic pain conditions. There is, indeed, a particular subgroup of chronic pain conditions which are more likely to be associated with depression: in syndromes such as fibromyalgia -where persistent and widespread pain appears to be related to changes in the CNS- it is acknowledged that psychosocial factors play a major role and antidepressants are more effective than in peripheral and nociceptive conditions such as osteoarthritis and rheumatoid arthritis. (Campbell, Clauw, Keefe, 2003: 401)

*Which came first, the chicken or the egg?*

In 1982, psychiatrists Blumer and Heilbronn publish a paper entitled *Chronic pain as a variant of depressive disease*. Here, the authors argue that chronic pain syndromes “with uncertain origin” seem to be perpetuated by an underlying central mechanism. Nevertheless, since there is no “plausible neurological theory of chronic pain beyond a highly hypothetical state” (Blumer, Heilbronn, 1982: 383), these conditions may be reasonably conceived of as a masked depressive state. The authors claim that these depressed patients experience the suffering in a physical way instead of in a psychological one; therefore, when no organic cause can be found, the physician has to suspect the presence of an underlying depression. To support their thesis, the authors quote several studies indicating chronic pain's comorbidity with depression, and suggest that this relationship is something more than a simple co-occurrence. Moreover, the fact that the relief for depression usually

concur with an amelioration of pain is another supporting evidence for a strong relation between the two conditions.

To support their thesis, Blumer and Heilbronn present a study based on a psychiatric and psychological evaluation of 900 patients conducted from 1973 to 1977. Recalling Engel's concept of the "pain-prone patient", the authors maintain that patients suffering from chronic pain "with uncertain aetiology" may be conceived of as an homogeneous group sharing common psychological features such as an hypochondriacal preoccupation for the painful body parts, and other psychological features already described by Engel.<sup>75</sup> In particular, these patients claim to feel often tired, anhedonic and helpless, symptoms which they tend to ascribe to their pain and not to depression. In the conclusion of the article, the authors give suggestions to the physician who deals with these patients: the doctor should not to do anything to make the patient believe that he thinks the pain to be imaginary, she has to explain to the patient that her pain "tends to be due to a malfunction *inside* the nervous system; that a depressive-tension state plays a role; and that it can be treated." (Blumer, Heilbronn, 1982: 391) The ideal management is based on the conjunction of antidepressants, behavioural therapy and an appropriate rehabilitation of the patient at work.

In four papers published from 1990 to 1994, Gamsa criticizes Blumer and Heilbronn's interpretation of elusive chronic pain syndromes as masked depressive states, as well as several other psychological theories conceiving of psychological

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<sup>75</sup> See 2.1.4 *Psychiatry and pain in the Sixties*

factors as causes of pain onset or at least of its persistence. (See Gamsa, 1990 for a review of psychological theories) Gamsa argues that most clinical studies aimed at proving pain's "psychogenicity" in chronic pain patients are highly questionable, because of methodological and epistemological problems. Concerning the methodological issues, Gamsa focuses on the presence of inadequacies in these studies, in particular due to the "absence of, or inappropriate control groups (...), conclusions concerning disturbance preceding pain onset based on post-pain testing- often with inappropriate instruments for patients with pain" (Gamsa, 1990: 183) and the fact that these researches often draw causal conclusions from data which are just correlational.

Gamsa's 1991 paper argues that Blumer and Heilbronn's "pain-proneness" is not scientifically demonstrable, by proving the groundlessness of the authors' two main arguments: the fact that psychosocial disturbances such as depression and anxiety in these patients "reflect life events before the pain and are thus significant in explaining pain onset" (Gamsa, 1991: 272) and that these patients represent an homogeneous group. The main features that are supposed to characterize "pain-proneness" in chronic pain patients are evaluated in a study based on four different questionnaires administered to 244 patients (163 suffering of chronic pain and 81 control subjects). The results show that of the twenty features prominent in the subjects described by Blumer and Heilbronn, only two of them -emotional repression and ergomania (a notably excessive work performance showed since childhood)- are consistently associated with pain, so these aspects have to be taken in account as

possible psychological precipitants or perpetrators of pain. Moreover, chronic pain patients are more likely to have relatives suffering from chronic pain. Gamsa concludes that, because of the intricacy of several features characterizing these conditions and the related treatment histories of these patients, a general caution in interpreting findings is needed. Furthermore, Gamsa argues, the perspective usually adopted in these studies, i.e. psychological factors are causes *or* consequences of pain, is useless: on a multicausal and integrated perspective, i.e. considering the interactions between different aspects, psychological factors may be both risk factors as well as consequences of pain<sup>76</sup>.

This issue is further tackled by Gamsa in her 1994 papers, where a review of several psychological theories put forward in the XX<sup>th</sup> century aimed at explaining the role of psychological factors in pain, is presented: psychoanalytical, behavioural, cognitive, and psychophysiological theorizations. Gamsa maintains that the main problematic aspect affecting most of these conceptions is a linear causal model postulating that pain could be caused either by organic factors or by psychological ones. From this perspective, those painful conditions without a known physical pathology are conceived of as mostly due to psychological reasons. Nowadays, as Gamsa remarks, important progress has been made in psychological research on pain and there is a relevant shift from the old linear causal model to a multicausal and integrated explanation of pain.

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<sup>76</sup> Gamsa's contention was supported by a relevant study by Hagedorn et al. In 1985 showing that the presence of the neurotic triad (depression hypochondriasis and hysteria) was not noticeable before pain onset

### *Biopsychosocial models*

In a widely quoted 1997 paper, Fishbain et al. review the scientific literature on the relationship between chronic pain and depression and conclude that studies indicate that it is more likely that persistent pain leads to depression rather than vice versa. From this literature review, Fishbain and colleagues indicate five main hypothesis put forward in scientific researches to explain the relationship between chronic pain and depression: i) the antecedent hypothesis: depression precedes chronic pain), ii) the consequence hypothesis: depression follows chronic pain, iii) the scar hypothesis: episodes of depression may occur before pain onset and predispose the patient to a depressive episode after pain onset, iv) the cognitive-behavioural mediation hypothesis: cognition mediates the relationship between chronic pain and the development of depression and, finally, v) the common pathogenetic mechanisms hypothesis<sup>77</sup>. The majority of reviewed studies support the consequence hypothesis, which may also be associated with the cognitive-behavioural framework. The scar hypothesis seems also to be potentially valid and it is corroborated by the finding that a relevant quantity of patients with a comorbidity of chronic pain and depression have relatives suffering from depression.

In 2003, psychiatrist Campbell and colleagues propose to integrate the results of Fishbain et al. with a framework proposed in 1996 by Banks and Kerns; here, the authors propose to explain the development of depression in chronic pain patients by employing the diathesis-stress model. In the third edition (2001) of *The Management*

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<sup>77</sup> Blumer and Heilbronn's theory is collected in this category



*of Pain*, Wasan, Sullivan and Clark indicate this framework as the leading model to understand the interactions between pain and comorbid psychopathology, including depression. Diathesis is a psychological theory which attempts to explain some behavioural features on the basis of a genetic predisposition (diathesis is a synonym of vulnerability) in conjunction with the stress brought by some experiences. In relation to chronic pain and depression, diathesis may include “negative schemas (...) attributions leading to learned helplessness (...) and/or deficits in instrumental skills.” (Banks and Kerns, 1996. Quoted in Dersh et al., 2002: 777) In this framework, chronic pain is seen as a powerful stressor which could trigger psychopathological issues in the individual pre-existent but which were dormant. According to the authors of the section on chronic pain and depression in the third edition of Bonica’s textbook, Wasan, Sullivan and Clark, the fruitfulness of this theory lies in its heuristic potential to explain the multiple relations between different factors in an integrative perspective. In the authors’ words, this model entails that “in any given person genetic susceptibilities to chronic pain and/or mental illness interact with the environment (...) leading to changes in the functioning of mental processes (...) and brain (...) resulting in chronic pain and psychiatric comorbidity.” (Wasan, Sullivan, Clarck, 2010: 401)

Explanatory frameworks such as the diathesis-stress model are currently considered on a scientific standpoint the most adequate conceptualizations of the relationships between chronic pain and mood disturbances such as depression. Nevertheless, in the perspective adopted in my work, the question is whether and

how theories are actually employed in dealing with specific chronic pain conditions. As it will be showed with reference to fibromyalgic syndrome, the fact that many physicians show to be aware of the multiple interactions between pathological factors in chronic pain, does not entail a management accounting for the several aspects of these conditions. Moreover, the employment of antidepressants in the management of chronic pain conditions such as fibromyalgic syndrome is usually clinically supported by a pragmatic perspective, i.e. if these drugs are beneficial, they should be prescribed. In this sense, even though the acknowledgment of the multicausal and integrated framework underlying chronic pain and mood disorders can be considered a step forward on a theoretical perspective, the issue of the comorbidity between chronic pain and depressions seems still far to be grasped.

*The distinction between chronic pain and depression: does it matter?*

In the scientific literature it is often claimed that studies aimed at explaining the relationship between chronic pain and depression may be insidious for the researchers: first of all, as Dersh et al. highlight, a troublesome matter is the fact that with the term “depression” one may refer to a mood, a symptom or a syndrome. As a result, the presence and the severity of clinical depression in chronic pain patients has been assessed through different types of tools which have led to a variety of results that are hard to compare. Chronic pain as well is a term which refers to a variety of conditions which, as it has been already indicated, are related to depression in different ways. An additional issue is what is defined as “criteria contamination” that may be caused by the frequent overlap of depression and

chronic pain symptoms, such as sleep disturbance, loss of energy, change in weight and appetite. Most of psychological instruments aimed at assessing depression, indeed, usually do not take in consideration the presence of a medical condition such as chronic pain.

As highlighted by Banks and Kerns, one of the most problematic aspects in this field of research is the lack of research tools appropriate for patients presenting a comorbidity of chronic pain and depression. In the conclusive remarks of their 1996 paper, the authors indicate indeed the necessity to use the DSM to assess depression and standardized measures of symptom severity, to make studies comparing depression rates between well-defined groups of chronic pain patients and control groups. as well as longitudinal studies focusing on temporal patterns of occurrence of the two conditions.

Wasan, Sullivan and Clark emphasize that low mood, impaired self-attitude and neurovegetative signs, i.e. sleep, appetite and concentration, are core symptoms of major depression in patients with pain as well as in patients not in pain. The clinical presentation of “Major Depressive Episode” in DSM-IV indicates that somatic symptoms, such as insomnia, have to be conceived as due to the depression unless it is clear that they are caused by a medical condition. Even if poor sleep, poor concentration and lack of enjoyment -often experienced by chronic pain patients- are usually attributed to the pain, the authors claim that, in any case, there is a *doubt* on the fact that these symptoms are due to pain. Hence, the authors conclude that “given the high rates of depression in chronic pain patients, in the context of low

mood complaints it is better to attribute these symptoms to a diagnosis of depression.” (Wasan, Sullivan, Clark, 2001: 397) This implies that even if some symptoms may be due to the pain instead that to depression, still the patient will receive a diagnosis of depression, as on DSM criteria the only way in which a patient with this clinical presentation does not receive a diagnosis of depression is if she has recently suffered bereavement.

Later in the chapter, the authors highlight that chronic pain sufferers often dismiss a diagnosis of depression because of the stigma that it may entail, but this issue seems not to be problematic in the authors' perspective: even if may be important for the patients determining “whether a depression is a *reasonable response* to life's stress” (Ibidem), and avoid therefore the potential stigmatization that a psychiatric diagnosis entails, this issue is worthless in deciding that treatment is “necessary and appropriate.” (Ibidem) Attempts to understand if chronic pain or depression came first is, in the authors' view, are beside the point (although this issue may be a useful information in a psychotherapeutic setting): if an individual meets the criteria for a *Major Depressive State*, then she will be consequently diagnosed and will receive the appropriate treatments. Moreover, there is “evidence that subsyndromal depression, i.e. depressive symptoms not quite satisfying the threshold for major depression but debilitating nonetheless, also benefits from treatment, and should be treated.” (Ibidem) Furthermore, the authors conclude, even if there are several studies showing that the depression is often consequent to pain onset, there are others indicating the contrary and others seeing a mutually reinforcing relationship.

From a clinical viewpoint, many authors remark that it is important to recognize the presence of a psychopathological state in chronic pain patients because an unrecognised depressive or anxious state may be problematic for rehabilitation; moreover, anxiety lowers pain threshold, may increase disability, and depression as well as anxiety may entail a magnification of pain symptoms. In the management of chronic pain conditions associated with depression, treatment options are mainly two: pharmacological approaches and psychosocial/combined treatments as cognitive-behavioural therapy. There is a significant evidence for the analgesic effect of tricyclic antidepressants in particular in the treatment of neuropathic pain and of those syndromes such as fibromyalgia, irritable bowel syndrome and migraine headache. Tricyclics have been shown to be particularly effective as analgesics in chronic pain conditions associated with serotonin-specific reuptake. (Fishbain, 2000) Even if studies on serotonin-specific reuptake inhibitors still present contrasting results, their employment is largely suggested because the effect seems to last longer and they also seem to be less toxic than tricyclic antidepressants. In any event, how these medications may act in alleviating both pain and depression remains highly debated: in a 2001 paper, Birket-Smith stresses that the most striking evidence against models such as Blumer and Heilbronn's is provided by studies on the effects of antidepressants on "chronic non-malignant pain"<sup>78</sup>: "the severity of pain does not consistently correlate with depressive symptoms, and studies have failed to support that depression is a specific risk factor for pain (...) successful treatment of

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<sup>78</sup> Here "chronic non-malignant pain" is employed as a synonym of "Somatoform Pain"

depression with antidepressants may not resolve somatoform pain. Correspondingly, treatment of pain with non-antidepressants may resolve pain but not the depressive symptoms.” (Birket-Smith, 2000: 1117) In a widely cited 2003 scientific literature overview<sup>79</sup>, Bair and colleagues indicate that most of the recent studies on the effect of antidepressants in chronic pain and depression indicate that improvement in pain symptoms is not directly correlated with an amelioration of depression in patients presenting with pain and depression. In the article, which specifically focuses on the comorbidity of chronic pain and depression, the authors conclude that on a clinical viewpoint, often the presence of pain may lead to the failure to recognize the presence of depression, and, therefore, to an undertreatment of it: “at least 75% of primary care patients with depression present with physical complaints” which “may be due to amplification of chronic physical disease and remain medically unexplained after extensive workup.” (Bair et al., 2003, 2441) In the authors' perspective, this issue is due to the lack of a “biopsychosocial” approach in clinical settings which would lead instead the practitioner to recognise the presence of both pain and depression, and therefore treat the patients not only with pain-relieving medications but also with antidepressants such as tricyclics. The authors conclude, that the main reason for this problematic situation, is the fact that often specialists have an expertise in treating pain or an expertise in treating depression.

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<sup>79</sup> This research has been significantly funded by Ely Lilly's funding and partially from other pharmaceutical companies selling the most well-known antidepressants

As claimed in the conclusion of the previous section, the question of the acknowledgment of chronic pain as a disease and its distinction from other conditions, e.g. depression, is influenced by several issues among which practical matters such as the management of these conditions in clinical practice as well as the structure of biomedical system which does not provide a comprehensive approach to the these conditions.

In the chapter of Bonica's textbook (2001) devoted to *Psychiatric illness, depression, anxiety and somatoform pain disorder* it is claimed that the relation between chronic pain, and psychiatric conditions is sometimes misunderstood because of

diagnostic hierarchies taught to physicians in medical schools and residencies, impairment rating strategies used by compensation systems, and the natural scientific method used by medicine that looks for objective causes for clinical phenomena force us into a mind-body dualism. (Wasan, Sullivan, Clark, 2001: 394)

The authors agree on the view previously presented that a disjunctive conception of chronic pain's aetiology may lead to the labelling of some chronic pains associated with psychiatric illnesses as psychogenic. The proper way to see the relationship between chronic pain and psychiatric illness is instead an inclusive one, that of a comorbidity between these conditions. Moreover, the authors emphasizes that the majority of patients with chronic pain and a psychiatric illness have a physical basis for pain in the body, whose perception is increased by the psychiatric condition. According to the authors of the section, one of the main reasons leading to the persistence of problematic approaches is related to the structure of clinical settings

which thwart the realization of an integrated (mental and physical) approach to these complex conditions. On a pragmatic perspective, this entails that chronic pain should be handled through a multidisciplinary approach, such as that proposed by Bonica for the pain clinic where several professionals, e.g. anaesthesiologists, psychiatrists and clinicians cooperate in the management of these patients.

### *Conclusion*

Multicausal explanations and the acknowledgement of the comorbidity of chronic pain and depression supported by biochemical findings seem to have solved the age-old matter of the relationship between pain and depression, but mainly on a theoretical level. Notwithstanding the progresses in the comprehension of this complex relationship, it seems in fact that this issue remains ambiguous. On the one hand, the effectiveness of antidepressants in the management of some chronic pain conditions is an important result from a pragmatic viewpoint. On the other hand, if it is assessed that a patient meets the criteria for depression, she has to be diagnosed and treated for it; moreover, receiving a diagnosis of chronic pain, e.g. fibromyalgic syndrome, or of depression appears highly dependent on the specialty framework of the diagnostician.

As it has been highlighted in the previous section, the dualism affecting biomedical approach to pain seem to be still present, even if it is no more explicated in the supposed Cartesian version of it; it has been argued, instead, that a dualistic approach to pain is noticeable in a disjunctive conception of pain aetiology which may be caused either by psychological factors or by organic ones. Moreover, such a



view witnesses for the fact that the acknowledgment of chronic pain as a disease in itself, has not been achieved yet; otherwise, the question would not be whether the pain is underlied by a depressive state or whether the depression is a consequence of the persistent pain. Furthermore, such a narrow perspective is supported and reinforced by the actual structure of biomedical institution grounded on the division of different specialties perpetrating dichotomic approaches in which complex conditions such as chronic pain ones do not fit.

The issue of the distinction between depression and chronic pain is a crucial topic, deserving a specific analysis considering the several aspects characterizing it which cannot be exhaustively tackled here. However a urgent question may be addressed: in the clinician's perspective, does the mentioned distinction matters? Once that it is acknowledged that some drugs may act alleviating both the symptoms of depression and the pain, does it make sense to keep the nosological entities distinct?<sup>80</sup> In the psychiatric field, for example, such a differentiation appears to be an old one, since nowadays biological psychiatry has somehow overcome this question by indicating the coincidence between the biochemical changes underlying several conditions usually considered as distinct. And what about the patients? Is it worth in their perspective to consider depression and chronic pain as different diseases? I have chosen to investigate this topic by conducting an observation in the Rheumatology Division of a local clinic with a focus on a specific chronic pain condition whose

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<sup>80</sup> For a remarkable analyses of the way in which antidepressants and their employment act defining and redefining depression as a nosological entity see Ehrenberg, 1998

problematic status as a disease I have been discussing, that is fibromyalgic syndrome.

## Chapter 4

### FIBROMYALGIC SYNDROME AS A DISEASE

#### 4.1 *Fibromyalgia: the unending story of a disease*

##### 4.1.1 *Introduction*

Fibromyalgic syndrome is a medical condition characterized by chronic widespread pain, reduced pain threshold (hyperalgesia and allodynia<sup>81</sup>), fatigue, sleep, cognitive and mood disturbances. Its prevalence is assessed between the 2 and the 4% of the world population with a particular incidence in the Scandinavian Countries and a lower one in the so-called Third-World Countries. (See Sordet-Guepet, 2004) Another relevant epidemiological data is related to the gender prevalence of fibromyalgia: female-men ratio is assessed approximately 6:1.<sup>82</sup>

The status of fibromyalgia<sup>83</sup> as a disease is troublesome; first of all, the recognition of fibromyalgia as a disease in biomedicine is contested: a quick look at the medical literature on the topic is sufficient to perceive the entity of the quarrel. This syndrome, i.e., a morbid entity defined by a constellation of symptoms, is mainly defined on the basis of its diagnostic criteria and its existence as a clinical distinct entity is widely debated. Moreover, even if nowadays researchers agree on seeing this condition and

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<sup>81</sup> Hyperalgesia is an increased sensitivity to pain and allodynia is the perception of pain consequent to usually non-noxious stimuli

<sup>82</sup> In my work I will not directly deal with the gender issue of fibromyalgic syndrome. In this regard, see Barker, 2005 and Greenlough, 2001

<sup>83</sup> Following medical literature, I use the terms fibromyalgic syndrome and fibromyalgia as synonyms

its multiple and diverse symptomatological manifestations as due to a dysfunction of the CNS, fibromyalgia's aetiopathology still remains highly controversial and widely debated and, consequently, also the place of fibromyalgia in biomedicine is far from defined. I have chosen to focus on this chronic pain condition precisely because of its problematic status in biomedicine; the analysis of the ways in which this condition is defined aims at making different levels of knowledge interact, by looking at the biomedical literature on it, at its clinical handling and, finally, at fibromyalgic sufferers' experiences of illness.

Unlike the analyses that I have pursued in the previous chapters, in this section I will only partially focus on history of the concept of fibromyalgia.<sup>84</sup> In this chapter, I move from a matter of fact, i.e. fibromyalgia has a problematic and contested status as a disease. Even if physicians, patients, medical and social textbooks keep on talking about fibromyalgia, it seems that nobody actually knows what fibromyalgia is, if anything like a fibromyalgic syndrome exists, which are its causes and, finally, which is the appropriate treatment for it. My discussion starts from here, in a grey zone from where I try not to take an a-priori stance but to review the different positions involved in the debate on the status of fibromyalgia as a disease, and move then to the analyses of fibromyalgia intended as an entity which comes to exist through the discourses<sup>85</sup> and, in particular, the practices approaching it.

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<sup>84</sup> Barker, 2005 provides in the first part of her work a detailed history of the notion of fibromyalgia. See also Moretti, 2013 (in Italian). Here, there is also a summary of the available literature in English

<sup>85</sup> I employ here the term *discourse* in the Foucauldian sense (Foucault, 1969) as used by Greenlagh (2001) as referring to an historically specific body of knowledge, that of biomedicine "that is made up of groups of

#### 4.1.2 A brief history of FMS

Even if the nosologic classification “fibromyalgic syndrome” (FMS) is quite recent<sup>86</sup>, the corresponding morbid entity characterized by a specific constellation of symptoms is much older. The history of fibromyalgia has been presented by different authors; most of them agree on tracing back the roots of contemporary fibromyalgic syndrome to the late XIX<sup>th</sup> notion of *neurasthenia*, term coined by US neurologist George Beard in 1869. In Beard’s view, *neurasthenia* is a medical condition resulting from the nerves’ exhaustion due to the stress of the modern civilization. (See Wessely, 1995: 508-531) Several other nosological classifications have been indicated as XX<sup>th</sup> century predecessors of fibromyalgic syndrome (See Sordet-Guepet, 2004; Barker, 2005): muscular rheumatism, *Psychogenic Rheumatism* (DSM-I, 1952)<sup>87</sup> and, finally, the more recent fibrositis. The term fibrositis was first proposed in 1904 by English physician Gowers to describe an inflammation of fibrous tissues and, even if it became soon clear that these tissues could not become inflamed, this term remained for quite a long time in the medical language, mainly indicating a form of psychogenic rheumatism. In a seminal article appeared in 1972 in *Arthritis and Allied Conditions*, Professor Smythe claims that it is possible to distinguish a particular form of fibrositis from the purely psychogenic one on the basis

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statements (...) that imit what can be said, written, and thought about illness and its treatment at a particular time.”

<sup>86</sup> Scholars usually date back the first proposal of this term to a 1977 seminal article by two Canadian researchers

<sup>87</sup> See 2.1.2 *Pain as a conversion symptom*

of a noticeable tenderness in particular locations in the body. The identification of these tender areas in the patients' bodies marks a relevant shift in the status of fibrositis as a disease: since then, this condition is not regarded as a psychogenic condition, but a different and poorly recognized rheumatic disorder. As Barker highlights, even if the relationship between tender points and muscular rheumatism was already present in the medical thought, Smythe's employment of the tender points' concept to identify a precise pain syndrome played a noteworthy role in the constitution of contemporary fibromyalgia. (See Barker, 2005: 23)

In 1981, Yunus et al. propose the term fibromyalgia (primary fibromyalgia) to describe a condition exhibited by patients complaining diffuse musculoskeletal aches, anxiety, tiredness, poor sleep and other symptoms; moreover, the physical examination shows the presence of multiple tender points with a precise location. This, in addition to the changeable presentation of symptoms, leads to a conclusive distinction of this condition from psychogenic rheumatism, characterized instead by a diffuse tenderness and by a major influence of psychological factors in the symptoms' modulation.

A crucial year in the history of fibromyalgic syndrome is 1990, when the American College of Rheumatology (ACR), composed by the most prominent fibromyalgia specialists of the time, presents the first formal diagnostic criteria for FMS. This article is the result of a multicenter study conducted in 1986 in 16 centers in the US and Canada on 558 patients, 293 previously diagnosed as fibromyalgic and 265 control patients. In the article, published in the prestigious *Arthritis and Rheumatism*,

the authors claim that FMS “can be identified, with good sensitivity (...) and specificity (...) from among the other rheumatic conditions by the use of simple criteria.” (Wolfe et al., 1990: 169) Fibromyalgia is defined by the ACR on the basis of two diagnostic criteria: i) the presence of widespread pain for at least three months<sup>88</sup> and ii) the painfulness of at least 11 of the 18 tender points<sup>89</sup> on digital palpation. Other recurrent symptoms found in the majority of fibromyalgic patients but not included as diagnostic criteria are: fatigue, sleep disturbances, “pain all over”, morning stiffness, paresthesias, anxiety, headache and irritable bowel. Modulating factors are cold/warmth, poor sleep, anxiety, stress, fatigue and weather change. Moreover, the distinction between primary and secondary fibromyalgia (fibromyalgia concomitant with another condition) does not appear to be relevant since that the criteria are applicable to both cases.

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<sup>88</sup> ACR points out that pain is considered “widespread” when is in both sides of the body and above and below the waist. Axial skeletal pain has to be present as well

<sup>89</sup> The location of tender points is that indicated by Smythe and Moldofsky, 1976



Tender points location (Wolfe et al., 1990: 169)

1990 criteria have soon become the worldwide standard for the diagnosis of fibromyalgia; nevertheless, their validity has been discussed since the publication of the ACR's article. 1990 diagnostic criteria define fibromyalgic syndrome by indicating the requirements that have to be met in order to make the diagnosis. At the same time, though, ACR does not define precisely what fibromyalgia is and gives instead a tautological and uninformative description of the syndrome by proposing diagnostic criteria obtained from a study on patients already diagnosed as fibromyalgic.

In 1992, during the Second World Congress on Myofascial Pain and Fibromyalgia, a working group composed by many of the 1990 criteria proponents puts forward a recommendation claiming that in FMS diagnosis physicians have to be flexible: in particular, when accompanied by other major symptoms such as headaches, Raynaud's phenomenon, restless legs, weakness complaints, tender points may be less than 11. Consequently to this claim, known as the Copenhagen Declaration,



fibromyalgia is included in the tenth edition of the ICD by the WHO (1992) in the section “Other soft tissue disorders not elsewhere classified” (code 79.7), without any specific indication concerning the symptomatology.<sup>90</sup> (See Barker, 2005: 26) Two years later, in the Classification of chronic pain syndromes by the IASP, Fibromyalgia is defined as a condition characterized by “diffuse musculoskeletal aching and pain with multiple predictable tender points.” (IASP, 1994: 45). Main features of FSM are i) chronic widespread and changeable pain, ii) fatigue, iii) stiffness (perceived as an increased resistance to joint movement), iv) multiple tender points, whose predictable location and multiplicity is a crucial feature of the condition, not detectable in other musculoskeletal syndromes.<sup>91</sup> The aetiology of FMS is unknown, even if today in scientific literature there is a propensity for a multi-factorial explanation, including a genetic predisposition associated with stressful events which could lead to the insurgence of the condition. Finally, IASP indicates that relief for these patients may be provided “by reassurances and explanation about the nature of the syndrome and possible mechanisms of pain.” (IASP, 1994: 46) In this way, anxiety can be reduced and multiple and expensive investigations and treatment can be avoided.

In 2007, the European League Against Rheumatism (EULAR) puts forward an “evidence-based recommendation” for the management of FMS, grounded on a systematic review of research studies on the treatment of fibromyalgia. The result of

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<sup>90</sup> Considering that fibromyalgia was previously classified as fibrositis, its inclusion in the ICD can be dated back to the ninth edition (1975) in the section *Other disorders of soft tissues*

<sup>91</sup> Other associated symptoms and signs are: paresthesias, headaches, irritable bowel syndrome, anxiety skinfold tenderness, reactive hyperaemia and autonomic phenomena

this work is a nine-points recommendation indicating that the best treatment for the condition includes: i) a comprehensive assessment of pain, function and psychosocial context, ii) a multidisciplinary approach with a combination of pharmacological and non-pharmacological approaches, iii) heated pool treatment, iv) individually tailored exercises and strength training, v) CBT in some cases, vi) relaxation, rehabilitation, physiotherapy and psychological therapy, vii) tramadol (an analgesic opioid) is recommended for the management of the pain, viii) antidepressants such as amitriptyline, fluoxetine, milnacipran among the others may help reducing pain and improving function, and, finally, ix) tropisetron, pramipexole and pregabalin may ameliorate FMS-related pain.

In 2010, the ACR puts forward a review of the 1990 diagnostic criteria for fibromyalgia<sup>92</sup>. This renewed framework is mainly due to the assessment of the clinical employment of 1990 criteria and of its limitations. The major changes brought about are: i) tender points examination is no longer required since it has been noticed that many physicians do not pursue this evaluation, ii) the introduction of the assessment of symptoms previously not considered as relevant which instead turned out to be prominent in fibromyalgic patients, i.e., cognitive disturbances, fatigue, waking unrefreshed and the severity of somatic symptoms; iii) a spectrum based evaluation of the condition in order to account for potential improvement in the patients' situation. The renewed proposal for the diagnosis of SF is grounded on three criteria which have to be contemporary present: i) a relationship holds between

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<sup>92</sup> See Wolfe et al., 2010: 607. Renewed diagnostic criteria are indicated in the Table 4

the Widespread Pain Index (WPI) and the Symptom Severity (SS) scale, where the latter indicator considers the severity of three core symptoms, fatigue, waking unrefreshed and cognitive symptoms, in addition to the somatic symptoms in general; ii) symptoms last for more than three months, iii) the pain is not explained by another disorder. In the conclusion, the authors precise that 2010 criteria proposal is not meant to substitute the 1990 one but to represent an alternative diagnostic option easily employable in the clinical practice. (See Wilke, 2009)

Fibromyalgia remains today an elusive condition, characterized by a wide constellation of symptoms whose predominant one is chronic and widespread pain. The collocation of FMS in the Rheumatology field, in virtue of the localization of the painful symptomatology in the musculo-skeletal system has led to a formal acknowledgment of it as a disease. Nevertheless, fibromyalgia status in biomedicine remains blurred: first of all, even though this condition has been lately framed as a dysfunction of the CNS, still an exhaustive explanatory model accounting for its wide and multiple symptoms, lacks. Second, fibromyalgia is a syndrome, i.e. a condition characterized by a constellation of symptoms, whose detection coincides with the definition of fibromyalgia as a disease. Moreover, the clinical management of FMS is based on the treatment of its symptomatological manifestations, especially of pain, when other pathological issues, currently recognized as crucial aspects of this condition such as fatigue and mood disturbances, are not directly addressed through specific therapies.

#### *4.1.3 Is there anything like a fibromyalgic syndrome?*

In a 2003 issue of *The Journal of Rheumatology*, three Editorials written by prominent US rheumatologists discuss the findings of a research conducted in an Amish Community, aimed at evaluating the hypothesis that FMS could be “symptomatic of a breakdown in societal values expressed by patients seeking disability compensation benefits.” (Gordon, 2003: 1665). This study shows that the prevalence of FMS in the examined Community, whose system is free from economic influences, does not significantly differ from the average; therefore, the assumption that the prevalence of FMS is proportional to economic matters, fails. However, the Editorials commenting this research are relevant since they may well represent the debated status of FMS as a disease. The evocative title of one of these articles, written by US rheumatologist Ehrlich titles *Pain is real; fibromyalgia isn't*. Here, the rheumatologist argues that fibromyalgia disease does not exist: FMS is instead a medical construct to account for painful conditions not otherwise explainable<sup>93</sup>. In the author’s view, this situation is related to the Western societies’ system which somehow creates a “fibromyalgia problem” by first diagnosing it, aggravating the patients’ problem by making them pursue useless examinations, certifying their disability and, eventually, leaving these individuals in a hopeless situation. A contiguous perspective is that of another rheumatologist, Hadler, who

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<sup>93</sup> Fibromyalgic syndrome is today recognized as a potential cause to grant disability benefits by the US SSA and by the UK Department of Work and Pensions. In 2009, the European Parliament presented a declaration aimed at recognizing FMS as a disease and, consequently, at pursuing actions to make its acknowledgment effective. This declaration has not been followed by an actual recognition of fibromyalgia as a disease. In Italy, the Autonomous Provinces of Bolzano and Trento have made a partial recognition of fibromyalgia as a disease by proposing a specific exemption code for it, entailing a statal participation to some of the medical expenses

claims that “the symptoms of widespread persistent pain should be heard as likely surrogate complaints for psychosocial confounders of coping.” (Hadler, 2003: 1669) As Ehrlich, Hadler sees the diagnosis of fibromyalgia as a “bad service” to the patients which mainly prevents them from improving by closing them down into a “diagnostic box” without any exit.

As Goldenberg sums up, the main concern of these authors is whether FMS diagnosis is disabling or enabling patients. (Goldenberg, 2004: 633) This contention does not recognize fibromyalgic syndrome as a disease but as the result of a socio-economical system which, by offering compensations to people claiming to be too ill to work, contributes to the creation of chronic conditions such as fibromyalgic syndrome. This argument may be paired with the “sick-role” one, holding that fibromyalgia goes to the detriment of the patients because it creates and reinforces illness behaviors and disability.

In a 2004 article in *The Journal of Rheumatology*, another prominent US rheumatologist, White, replies to the critiques of what he defines as “the anti-FM movement” by discussing several arguments which have been proposed against the label of fibromyalgic syndrome. First, White considers the “objectivity issue”, i.e. the thesis that FMS should not be considered a disease because of the lack of objective physical findings accounting for it. According to the author, this problem does not only affect FMS but many other conditions; moreover, White contends that the absence of objective indicators assessing the presence of fibromyalgia is false: clinical studies on these patients have showed instead the presence of measurable

alterations in skin tissue compliance and other pathophysiological issues such as alterations in brain wave activity, hormonal and biochemical changes. A second objection to the validity of FMS label is that this condition is a psychological one and that therefore its disease status should be revised according to. White's counter-argument is the old -but seemingly always convincing one in the biomedical literature- indicating the inconsistency of a clear-cut distinction between psychological and physiological conditions; in a "biopsychosocial" perspective, White claims, the distinction mental/organic disorder is meaningless. As highlighted in the section *3.3.4 Chronic pain and dualism: which dualism?* of the present work, the allegation to pursue dichotomic approaches to disease entailing clear-cut distinctions between organic and psychological conditions is very common in the medical literature. Usually, the detractors of this view argue for the need to employ a biopsychosocial approach to disease. Unfortunately, in most of the cases, this claim remains on a theoretical level and does not takes in consideration the actual obstacles to the application of a biopsychosocial approach to the patient such as the insurmountable boundaries between medical specialties in the clinical practice. In general, the label "biopsychosocial" in medical literature is usually employed without the necessary reflection on what approaching disease in a biopsychosocial perspective would entail and therefore, it often turns into a rhetoric and sterile argument.

The power of the "psychogenic" argument has been reinforced in the years by many research findings indicating the beneficial effects of some antidepressants in

the treatment of fibromyalgia<sup>94</sup>. In June 2007, FDA has approved Lyrica (pregabalin) as a specific drug for fibromyalgia and, one year later, the same has happened with Cymbalta (duloxetine hydrochloride). (See FDA, 2008). Lyrica was previously employed in the seizures' treatment and neuropathic pain such as diabetes-related one, while Cymbalta is a SNRI and is widely used in the treatment of depressive and anxiety disorders. As already highlighted<sup>95</sup>, the comorbidity of chronic pain and depression is a controversial topic. Even if nowadays it is widely known that the relationship between these conditions has to be interpreted in an integrated perspective, i.e. neither pain causes depression not vice versa but pathological and mutually reinforcing mechanisms underlie their co-occurrence, still this issue remains to be tackled, especially in relation to the potential stigmatizing character of an antidepressants' prescription. This topic will be analyzed in the next section where I will discuss the findings of my observation of clinical encounters in a Rheumatology Division of a local clinic.

#### *4.1.4 Fibromyalgia as a central sensitization syndrome: is "the answer not blowin' anymore in the wind?"<sup>96</sup>*

In 1989, one year before the publication of ACR diagnostic criteria, Wolfe describes fibromyalgic syndrome as a musculo-skeletal disorder. After almost a

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<sup>94</sup> In the medical literature, the best therapeutic approach for FMS is usually indicated as a multimodal one constituted by pharmacological and non pharmacological treatments such as antidepressants, muscle relaxants physical activity and CBT therapy

<sup>95</sup> See 3.2.6 *Chronic pain and depression: a digression*

<sup>96</sup> Here I refer to White's previously mentioned article titled *Fibromyalgia: the answer is blowin' in the wind* which, of course, is taken from Bob Dylan' famous song

century of debates on the status of fibromyalgia as a disease -mainly grounded on a psychogenic interpretation of the condition- FMS has finally found a place in biomedicine: fibromyalgic syndrome is a rheumatologic condition with a problematic aetiology (almost unknown), but definable on the basis of precise diagnostic criteria.

As Barker remarks, after the publication of ACR 1990 criteria, researchers' interest in fibromyalgia has significantly increased (See the diagram in Barker, 2005: 28); the most common factors studied as associated to or causing FMS are: i) neurobiologic, ii) muscle disorders, iii) infection, immune-related, iv) psychological and behavioural and, finally, v) sleep disorders. (See Barker, 2005: 29)

In a 2001 article, fibromyalgia expert Muhammad Yunus proposes to consider FMS as a dysregulation spectrum syndrome, i.e. as part of a wider spectrum-syndrome in which "some common underlying mechanism manifest itself in hypersensitivity to a wide range of sensory stimuli". (Yunus, 2001: 130. Quoted in Barker, 2005: 33-34) Yunus moves from the frequent association of fibromyalgic syndrome with conditions such as chronic fatigue syndrome (CFS), irritable bowel syndrome (IBS) and tension type headaches (TTH), among the others. From a review of the existing medical literature using several keywords such as "functional somatic syndromes", "psychosomatic pain" and "somatization", the author argues that all these labels may be substituted by that of Central Sensitivity Syndromes (CSS) one: this term defines those conditions due to a dysfunction of the CNS which entail abnormalities in sensory processing and therefore, also in the perception, integration and transmission of pain. Central sensitization mechanism may be



activated and/or maintained by a multiplicity of factors, including: i) genetic predisposition, ii) neuroendocrine dysfunction, iii) psychological factors such as anxiety, depression and stress, iv) physical or psychological traumas (See White et al., 2000), v) inflammatory conditions, vi) environmental factors. (See also Bennett, 2004) All these issues may trigger or contribute to the central sensitization mechanism which may cause the insurgence of a CSS. This condition, which is chronic and therefore persists, may in turn act by exacerbating the central sensitization processes. (See Yunus, 2007)

The impact of this novel conceptualization of the morbid process underlying fibromyalgia is noteworthy: as Bennett maintains, “fibromyalgia could become the classic example of a revised definition of disease that embraces disorders characterized by abnormal neurophysiology.” (Bennett, 2004: 379) In this sense, the debate on the status of FMS as a disease appears to be close to the end: fibromyalgia is a disease but not a disease in the traditional sense, i.e. an entity distinguishable from other conditions and characterized by specific features. According to Bennett, this is not an issue in itself but a contingent problem due to a shift of paradigm that will brought about a new conception of disease not grounded anymore on criteria such as that of the delimitation between clinical entities. This change of paradigm will broaden biomedical conceptualization of disease by including conditions such as FMS which are not organic or psychological but, with the happiness of the “biopsychosocial” approach proponents, both of them<sup>97</sup>. Moreover,

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<sup>97</sup> See Yunus, 2007: 346-347. Here, the author evaluates the hypothesis to consider also depression a CSS

biomedical semiology will be reshaped by abandoning Bichat's model (pathology means lesion) for a renewed medical gaze which will search for the sign of disease in processes, alterations and dysfunctions no more in damaged tissues but in changes in the normal functioning<sup>98</sup>, in particular at a neurophysiological level. Finally, as Yunus and others triumphantly claim, evilish dualisms (disease-illness<sup>99</sup> and mind-body) which have affected for so long biomedicine will be finally defeated.

Such a scenario appears at least optimistic, also because it is clear that claiming that dichotomic conceptions of pathology should not be supported, does not entail to actually overcome them; as it has been stressed throughout the course of this work, the awareness of the narrowness of a dualistic conception of the relationship between mind and body in disease is today widely shared, at least in the scientific literature. Nevertheless, the fact that this theoretical shift of paradigm has not led to an actual one, witnessed e.g., by controversies on the disease status of fibromyalgia, clearly indicates that dualism transcends conceptions and theories and lies instead in something of much more deeply rooted in biomedicine.

#### *4.1.5 Conclusion*

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<sup>98</sup> In this regard, Canguilhem's *The normal and the pathological* remains a crucial reading

<sup>99</sup> Yunus' conception of disease/illness dualism is a peculiar one, since that he defines disease as grounded on a structural pathology and, conversely, illness as something which is not related to such a pathology. In the social sciences, instead, "disease" is usually conceived as biomedical interpretation of the pathology in terms of biological abnormalities in the structure and functions of the body while illness is its parallel dimension which identifies the sufferer's experience of disease as a "disvalued changes in the state of being and in social function." (Eisenberg, 1977. Quoted in Sullivan, 1986:332) Yunus conception of the contrasting poles in biomedicine seems to be more adequately referable to the organic/non organic issue

The recognition of fibromyalgia as a disease has been possible by framing it in a much wider spectrum of conditions, such as CFS, IBS, Post Traumatic Stress Disorder (PTSD), multiple chemical sensitivity, temporomandibular disorders (MPS). What these conditions have shared up till now is the acknowledgment of their problematic status in biomedicine: they have been labelled as “medically unexplained”, “functional somatic syndromes” and also “psychogenic”. As Sordet-Guepet points out, it appears that every medical specialty has its own functional somatic syndrome: FMS in rheumatology, IBS in gastroenterology, premenstrual syndrome and chronic pelvic pain in gynecology, MPS in dentistry and so on (See Nimnuan, Rabe-Hesketh, Wessely, Hotopf, 2001); Sordet-Guepet suggests that these “unexplained” conditions are an artificial construct due to the hyperspecialization of medicine (Sordet-Guepet, 2000 : 679), i.e. these conditions exist only in a system such as biomedical one, which divides and assigns every section of the body to a section of medicine. This entails that the underlying criterion defining where, who and how a pathology is treated is the localization of the morbid process in the patient’s body. The mentioned conditions result unexplained because the symptoms’ localization, e.g. FMS in the musculo-skeletal system, IBS in the bowel, does not coincide with a detectable injury in that part of the body, which, nevertheless, hurts. Therefore, biomedicine finds itself without adequate explanations and this may lead to maintain, by the way of an exclusion reasoning, that the pathology is in the patient’s mind. CSS framework indicates a shared aetiopathological mechanism underlying all these conditions (and accounting for their common fundamental

symptom, pain), and seems therefore to be the solution to the “medically unexplained” conundrum. Moreover, as Winfield claims, CSS theory may also represent a relief for patients affected by these conditions who, finally, won’t have to feel anymore “ashamed of their diagnosis. It is not biological or psychological. It’s all biological!” (Winfield, 2007: 337)

Regrettably, such an optimistic scenario appears futuristic, if not utopian: even if CSS model has proven to be fruitful in an heuristic perspective, this does not entail also a better understanding of how to treat these conditions, at least not yet. A given set of antidepressants, while effective, may turn out to be inadequate if, on the one hand, they relieve symptoms, but, on the other hand, bring about serious side effects e.g. at a cognitive level. Integrated approaches are repeatedly presented as the best treatment option for these patients but, as it will be showed in the next section, in the clinical practice multimodal approaches lack.

Even if one day CSS renewed perspective will be widely embraced in biomedicine, as a matter of fact the condition sine qua non for an actual application of this model is a wholly renewed biomedical system. Nowadays, the boundaries separating different medical specialties appear instead even more reinforced and, consequently, an adequate allocation of these conditions in biomedicine, is far to come. Finally, the supposed redeeming character for stigmatized patients following a reconceptualization of these conditions as biological, has to be proven yet. As scholars such as Kirmayer emphasize, the ascription in biomedicine of moral values to mind and body and their role in disease is rooted much more deeper than in a

theoretical paradigm such as the Cartesian dualism. Notions such as that of individual responsibility, which is crucial in relation to the definition of what a disease is, is strongly embedded in our way of living, and biomedicine mirrors it. Finally, a variable which has to be taken in account is the practical character of biomedicine: the definition of an entity as a disease takes form also in the clinical practice of medicine, along with and, sometimes, clashing with the theories. This is the perspective which underlies the research that I present in the next section, where I will discuss the findings of an observation conducted in the Rheumatology Division of a local clinic.

## 4.2 Fibromyalgic syndrome in Rheumatology

### *4.2.1 Introduction*

This section focuses on the clinical interactions between rheumatologists and fibromyalgic patients, in the attempt to investigate how fibromyalgia is defined in the clinical practice. As anticipated in the previous section, the very existence of fibromyalgia as a disorder is debated in biomedicine. Nevertheless, under a certain respect, fibromyalgic syndrome exists as much as rheumatoid arthritis (RA) does, as a pathological condition affecting the musculo-skeletal system and therefore dealt with in Rheumatology.

My analysis looks at fibromyalgia as “a part of what is done in practice” (Mol, 2002: 13), i.e. instead of addressing the issue of the “reality” of the disease, I try to point out the main features constituting what fibromyalgia *is* in the clinical practice. The best metaphor of my analysis is that of the game in which one has to discover a figure by

linking all the points. The indicators describing fibromyalgia include both the standard diagnostic criteria for FMS as well as references usually not included in the clinical definition of the disease which however concur in defining this entity.

In the following pages, I will present the findings of an ethnographic enquiry conducted in a rheumatologic day hospital, a subdivision of the Internal Medicine Department of S.Orsola-Malpighi Policlinic<sup>100</sup>. Here, I conducted a participant observation of the clinical encounters lasted nine months. During this period, I had the occasion to observe a total of 105 encounters, about 1/5 of which with fibromyalgic patients. My narration of the observation will deal only with the clinical consultations of fibromyalgic patients even if the other encounters I witnessed to will be sometimes mentioned and constitute a pivotal reference for my analysis. The reader will find a report, as objective as possible, of the interactions and, alongside, in italics, the discussion of some issues arisen from the consultations which I have found to be worthy to stress, in addition to some self-reflexive analyses on the investigation that I have run.

Unlike the previous chapters, here I will not refer to any specific academic scholar or book. Many ethnographic enquiries have been conducted on pain, e.g., the collection of anthropological essays on pain experiences edited by DeIVecchio-Good, Brodwin, Good and Kleinmann (1992), the analyses of the anthropologist Jackson on chronic pain sufferers (1992; 2001) and the enquiry of the sociologist of medicine Barker on fibromyalgia (2005). All these works, already indicated in the previous

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<sup>100</sup> S. Orsola Malpighi Policlinic is one of the main hospitals in Bologna

chapters, underlie my research. Moreover, three main references may be indicated as motivating, underlying and sustaining my analyses. The first is Isabelle Baszanger's already mentioned work on the constitution of pain medicine, which couples an historical-critical analysis of the rising of pain medicine in the US with an in-depth ethnographic enquiry on pain medicine in France. My second authoritative reference is Annemarie Mol's *The body multiple: ontologies in medical practice*, a clever analysis of how a specific condition, arteriosclerosis, is enacted in practice, i.e. an analysis of how a disease may "come into being –and disappear- with the practices" in which it is manipulated. (Mol, 2002: 5) The third landmark is a training course in qualitative methods for the research in the social sciences I have attended during a visiting period at Lancaster University. Here, I had the occasion to integrate my knowledge in the ethnographic approach, by studying the several tools of investigation available to social scientists. A discussion of the methodologies that I have employed throughout my work will be tackled in the Conclusion of the dissertation.

#### *4.1.2 Fibromyalgia in the Rheumatology division: an ethnographic enquiry*

The Rheumatology Unit where I conducted my observation is composed by six permanent Rheumatology specialists, a nurse, a physician who occasionally participates to the consults, and a medical student. The main activities of the day hospital are the clinical consultations (first visits and follow-up), in addition to some exams such as capillaroscopy and ultrasound. The patients admitted are usually sent here by their general practitioner (gp) for the suspect of a rheumatic problem, or they

are returning patients followed by the doctors of the clinic. Most of the times, patients come back for cyclic controls every six months, or every three, if their health condition requires so. The average duration of a clinical encounter is about one hour and the encounters run in every consultation room (four in total) are between five and seven every morning<sup>101</sup>. Consultations are conducted by one rheumatologist or, more often, by two; from what I have seen, the environment is collaborative and the physicians often discuss about the cases, especially if the patient has been visited before by another doctor. Following the standard treatment of rheumatic diseases, the approach is pharmacological, even if advises on potential complementary therapies or further medical investigations are indicated to the patients. The therapy is usually based on a specific medication for the rheumatic condition accompanied by analgesics to control the pain, which is the predominant symptom.

I have witnessed to my first consultation of a fibromyalgic patient during the first day at S. Orsola. While I was in the consultation room with Doctor G., Doctor M., the Chief of the Unit, came and told me to go with her, because she was visiting a FMS patient in another room.

The first thing that stroke me was the young age of the patient, a 24 years old girl. The girl was sent to Rheumatology for a consult from Orthopedy because of a pain in the left side of her neck. As the girl started telling her medical history, it became soon clear that her pain condition was much more complex: the neck pain was lasting for

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<sup>101</sup> Clinical consultations are usually run also in the afternoon but only from 2.30 pm to 4.30 pm and in specific days the afternoon consultations are devoted to specific patients, such as those with arthritis or dermatologic patients. Except for one afternoon, I always went there in the morning



12 years and she also suffered of frequent headaches diagnosed in the years as musculo-tensive or as due to somatization. Lastly, she had started having pain also in the left arm and in the left leg, and this thwarted her from driving. She often had muscular cramps and paresthesias when lying in the bed, so she could not properly rest. When the situation worsened, she went to see a neurologist who made her a head CAT<sup>102</sup> but *the result was negative*. To control the pain, the patient took different painkillers and sometimes she also made some analgesics' injections. The neurologist changed her therapy and gave her Topiramate, an anti-convulsant drug.<sup>103</sup> While the patient kept telling about her pains -which were actually affecting all her body-, she showed the results of the different exams and analyses done throughout the time, all collected in *a very thick dossier*.

*The presence of a very big dossier is for the doctors a distinctive sign characterizing fibromyalgic patients. The dimensions of the dossier are directly proportional to the number of analyses and exams run in the years by these patients in order to find a cause for their distress. In the majority of the cases, though, all the examinations' findings are negative. As a matter of fact, the absence of any organic finding accounting for the patients' symptoms, and, in particular, the distressing and widespread pain, is a criterion in the rheumatological practice supporting a fibromyalgia diagnosis.*

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<sup>102</sup> Computerized axial tomography

<sup>103</sup> Topiramate is indicated in the EULAR Recommendations in the treatment of fibromyalgia

After the anamnesis, the doctors started asking the patient about her general health condition. The pain, the patient claimed, was worst when she was in the bed. The reason, in her opinion, was that in that moment she paid more attention on herself. This appeared important to Doctor M., who kept on asking the patient about this aptitude of *"listening a lot to herself"*. In the Doctor's view, this could be the origin of a vicious circle, so that, the more the patient listened to herself, the more she felt the pain. The consult went on with the standard physical examination through which 14/15 tender points appeared painful and other typical indicators of FMS were found: hyperlaxity in the ligaments and disturbed sleep. The term "fibromyalgic syndrome" came out only at the end of the consult, when the physician asked the patient if anyone had ever spoken with her about this condition. At first, the patient said no, but later she remembered of a gastroenterologist who visited her when she was 15 who told her that she could have FMS. Doctor M. confirmed this diagnosis: "the clinical examination points at a fibromyalgia diagnosis. If the exams are negative, the hypothesis is further supported." When the patient went out, the doctors discussed with me about the case and concluded that there was nothing organic accounting for a pain which seemed that of a sciatalgy. Also, Doctor M. stressed that it was very strange that a young girl was so concerned about her body.

*An heightened attention towards one's own body appears to be an issue shared by many fibromyalgic patients; moreover, this attitude is conceived by many physicians as one of the factors promoting FMS' pathological symptoms. Somatic*

*concern is indicated also as a crucial feature of conditions such as Pain Disorder<sup>104</sup> and Chronic Pain Syndrome. However, clinicians never explicitly referred to these psychiatric classifications, even if this feature was indicated as a pathological inclination of many FMS patients. Advises on how to deal with it were also frequently given, such as avoiding indoor activities and doing instead any kind of thing that could help them to distract, for example outdoor physical activities with other people.*

At the end of my second day of observation, Doctor M. called me again for another consultation. The patient, an Hispanic 60 years old woman, was accompanied by the pregnant daughter-in-law. I came in late so the Doctor was already pursuing the physical examination: at every touch of the physician, the woman *screamed*.

*ACR diagnostic criteria for FMS indicate that at least 14 on 18 tender points have to be painful at the digital palpation. In the encounters that I witnessed to, this actually represented a pivotal tool for the diagnosis of fibromyalgia; nevertheless, according to the 2010 criteria revision (ACR, 2010), painful tender points may be less than 14 in order to diagnose FMS if the clinical presentation includes other relevant symptoms such as fatigue, cognitive and mood disturbances.*

*The painfulness of tender points in fibromyalgic patients is typically associated to hyperalgesia; when the doctors make pressure on these specific areas of the patient's body, the reaction is usually overwhelming: most of the patients tense up,*

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<sup>104</sup> Even if in DSM-IV' *Pain Disorder* classification this criterion is not explicitly mentioned, still it was in the previous categorization (DSM-III *Somatoform Pain Disorder*) and in the proposed DSM-V revision of *Pain Disorder, Complex Somatic Symptom Disorder*. See Chapter 2, section 2.2 *Psychogenic pain in the DSM: is Pain Disorder a valid classification?*

*others shout, other ones are almost crying. This does not usually happen with other rheumatic patients, whose reactions to pain are more controlled, even when the doctors makes pressure on the damaged body parts.*

The patient was taking Medrol (metilprednisolone) for 3 years and an anti-inflammatory analgesic. The patient showed typical FMS' symptoms such as pain-all over and tiredness, but she had also swollen fingers which could indicate the presence of an inflammatory condition. At the end of the consultation, Doctor M. told the patient to come back after 6 months with the results of the hands' X-Ray. The daughter-in-law asked if it was not possible to come back earlier, when they had the tests' result, but the Doctor replied that "anyway, *the findings will be negative.*" The girl asked if the pathology -which had never precisely indicated by the Doctor before- was severe, and the Doctor reassured her by saying that they were trying to figure out if the problem was inflammatory or if it was a FMS, *a benign pathology* which would have caused to her mother-in-law pains, but not deformities. It was very probable, though, that the patient had fibromyalgia, since Medrol had never worked.

*Throughout the course of my enquiry, I have heard doctors defining fibromyalgic syndrome in different ways, which I will emphasize and discuss. In the last consult, the Doctor employs the adjective "benign" in order to distinguish fibromyalgia from other conditions considered malignant such as LES or arthritis, because of their degenerative course. The constellation of symptoms characterizing FMS is fluctuating, so fibromyalgia cannot be defined as progressively worsening. The degenerative course of malignant conditions, though, usually refers to the underlying*

*pathological process, which may be manifested by the symptoms. The morbid process underlying fibromyalgic syndrome is a dysfunction of the CNS which does not follow the malignant-degenerative trend: this pathological process resembles more that of a mechanism which has broken and keeps on sending wrong messages, causing an altered perception of the sensory information.*

*At any event, fibromyalgia is, as the majority of rheumatic condition, a chronic disease whose morbid process gives way to a self-sustaining vicious circle of pathological manifestations. It is worth to remark that FMS, as the majority of chronic pain conditions, owes its pathological status not to the acknowledgment of the underlying morbid process, such as an inflammatory one as in arthritis, but to the presence of several disturbances at a symptomatic level.*

That week I went to the clinic another time. While I was with Doctor R., Doctor M. came and asked me again to follow her because she was visiting a fibromyalgic patient who she wanted me to meet. Doctor M. asked the patient to tell me about her story: the patient, a 40 years old woman, told me that after years of suffering, she decided to go for psychotherapy “in order to make peace with the emotions in my life. After the second consult, my pain went away.” Before, she took an antidepressant in the morning and Tramadol in the evening, and still her pain did not cease. “I knew that there was something related to fibromyalgia... also the doctor believed that I had to see a psychotherapist. Since 1996, it was the first time that I didn’t have pain. Living that way was an emotional and a physical distress.” In 2008, the patient was diagnosed RA and FMS, the latter, treated with Tramadol. Doctor M. invited me to

ask questions to the patient but, even if this patient's case was quite interesting, I felt uncomfortable in that position. My feeling was that the Doctor wanted me to know about that case because it was emblematic of how fibromyalgia could be cured when the patient was treated psychologically. So, I asked the patient without particular conviction what having to work in that condition was like and I got a reply as trivial as the question I posed: the job was a problem, she often had to miss it because she was too tired, but after the psychological therapy she started again being active and going to work. "What changes is the approach that one has to everyday situations", the patient concluded.

*After a further reflection on this case, I realized that in that occasion I acted silly. I had felt somehow offended by the fact that, in my view, the Doctor was trying to show me that fibromyalgic patients were mainly people with psychological issues. Moreover, I felt annoyed by the compliance showed by the patient to the physician's perspective, i.e. that her health problems were wholly psychological. At that time, I was only at the beginning of my observation and I had a clear-cut perspective on fibromyalgia issue, characterized by a strong prejudice towards medics and a compassionate attitude to the patients. My perspective led me to side for the patients as victims of a double torture, that of having fibromyalgia and that of being seen by the doctors as crazy. The more my observation went on, the more I realized that the question was much more complicated, and that FMS was puzzling and problematical for patients as much as for physicians.*

*In my ethnographic enquiry, the link between FMS and depression is an aspect to which I have paid much attention. It is worthy to recall that the use of antidepressants is indicated in the treatment of FMS patients and this does not imply seeing fibromyalgia as a form of masked depression. The doctors of the Unit often prescribe these medications to these patients, sometimes specifying that this is not because the patient is depressed, but because of the proved beneficial effect of these drugs for her condition. The way in which patients deal with an antidepressants' prescription can vary: in some cases, they just accept to take them as the best treatment available for their condition, without explicitly questioning the meaning of a cure for depression. Some patients, instead, have troubles in accepting this therapy. Physicians in general take a pragmatic stance in this regard, i.e. if these drugs work, one should just take them, even if, when it comes to the treatment of specific patients, also physicians show to have more complex perspectives on this issue.*

The day after my troubled observation, I witnessed to another consultation of a FMS patient. The woman was about 40 years old and came with her mother. Her symptoms started in 2009 with a pain located in the thorax and in the left arm. At first, she believed that she was going to have a heart attack, but the exams showed no abnormal cardiac activity. Recalling that period, the patient indicated a chicken pox got by her 3 years old son as *the triggering cause* of her problems.

*The issue of fibromyalgia's triggering cause is much debated in the medical literature. As indicated in the first section of this chapter, scientists propend today for*

*a multi-causal explanation of fibromyalgia as related to the presence of predisposing factors which, after a traumatic event, may lead to the insurgence of the condition. When asked, FMS patients are usually able to indicate a specific occurrence as the provoking cause which, as indicated in the medical literature, may be a physical trauma such as an infection, as well as a psychological one, as a troublesome divorce.*

*When thinking about the topics that I wanted to analyze during my fieldwork, the issue of pain causation was at the top of the list: my analyses of the problematic acknowledgment of chronic pain as a disease in biomedicine had led me to conclude that aetiology was a crucial matter. My hypothesis, while approaching the ethnographic investigation, was that the biomedical framework carried on a narrow perspective grounded on a dichotomic view of pain aetiology. This entailed a failure in comprehending chronic pain as a disease, because this condition was characterized instead by a multiplicity of different and intertwined causes, both physiological and psychological. I wanted therefore to unravel physicians and patients' conceptions of fibromyalgia causation in order to show the differences between these perspectives and remark on the restrictedness of the biomedical approach.*

*When observing and speaking with doctors and patients, I realized that the most interested person in this topic, was me. Obviously, during the clinical consultations, this matter came out implicitly many times. Nonetheless, the supposed overwhelming gap between organic and psychological causes never emerged as an a-priori*



*distinction between organic disorders and psychogenic ones. As already anticipated, the gap between FMS and other rheumatic conditions in the physicians' perspective was mainly related to a pragmatic issue, i.e. if the psychological treatment works, then it has to be pursued, since it is the most appropriate. The organic/non-organic distinction emerged in relation to the fact that when biomedical tools could not detect a morbid process accounting for the patient's distress, physicians simply did not know how to act and, therefore, concluded that the patient should take analgesics to control the pain and antidepressants -if they were beneficial- or see a psychologist.*

As for the majority of fibromyalgic patients, the woman's medical history was very troubled: the pain worsened during the night so that she could never properly sleep; during the year, the symptoms were fluctuating and particularly bad in the colder months, fading and reappearing in coincidence with her period and the season change. Moreover, she often felt a sensation of oppression in her chest that the Doctor ascribed to fibromyalgia. All the pharmacological treatments caused her collateral effects which forced her to stop taking them. The Flexiban, a miorelaxant employed in the treatment of FMS, gave her nausea; Contramal (tramadol) caused her hallucinations while antidepressants such as Lendronal, Lexotan and Xanax, caused her allergic reactions. The patient wanted to try alternative treatments so the Doctor suggested her to do thermal baths and muds, whose cost was also partially

covered by the National Health Service<sup>105</sup>. However, Doctor R. told the patient that if this did not ameliorate her condition, they would have to reconsider taking the Contramal.

A major preoccupation of the patient was her *job*. Every time she had a strong attack, she had to stay at home for one week, but, after a while, her gp and her boss started thinking that she was feigning. “I need you to write a certification attesting that I have a condition which forces me to stay at home to rest for some days after the acute phases.” Doctor R. wrote down the certificate claiming that the patient was affected by FMS and that she needed rest and periodic controls. However, the Doctor said, “this certificate has a limited value; it would be much useful if I write instead that you have a reactive depression caused by fibromyalgia because mental diseases are more taken in account than organic ones...” This explanation convinced the patient who agreed that the depression was a reaction to her distress: “when I was fine, I felt great, I did a lot of things... when I feel good, I do feel good.”

When the patient went out, Doctor R. told me that this patient’s case puzzled her: the woman had a good education, a good family and a job that she seemed to like even if she was putting all of these at risk. “Every time she comes, she has run new tests and exams because she wants to find the cause of her pain, but they are *always negative*. I would really like to help her, but it’s impossible if she refuses to go to the psychotherapist.”

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<sup>105</sup> To my knowledge, this is the only exemption that fibromyalgic patients may use. Patients can get for free once a year thermal care. However, this therapy is not specific for fibromyalgia, but it is provided for the so-called extra-articular rheumatisms

*The job is a very frequent topic in the patients' discourses. As in this woman's case, the issue emerges in relation to the lack of recognition of FMS as a disorder. The national healthcare system recognizes exemptions for the payment of some treatments or for specific analyses to patients i) having particular chronic and invalidating conditions and ii) having rare diseases, iii) on the basis of the age and/or iv) of the patients' income. The patient may ask for the exemption by presenting a medical certificate attesting that her condition is included in the list put forward by the Minister of Health. Fibromyalgia does not figure in the list.*

*Another way to get some facilitations is by asking for the disability recognition. In Italy, a citizen may claim for disability when having an handicap or an invalidity which has to be assessed by a specific Commission. This may entail different facilitations concerning the access to therapies, the job, social supporting, and parenting (law 104 for handicap, law 118 for the invalidity and law 68 for the right to work). Fibromyalgic patients formally can claim for disability, since the functional (physiatrist) and psychological (psychiatrist) issues consequent to FMS are taken in account in the process of disability recognition. Nevertheless, during my observation, I realized that the majority of patients and physicians are not aware of this procedure, so fibromyalgic patients usually do not get any kind of facilitation.*

The following day, I was with Doctor B., a specialist in osteoporosis. After a consult of a patient with RA, the Doctor asked me if I wanted to follow her in another room because she had to go visit some patients who have had a heart transplant; I asked her if she thought that any of them could have fibromyalgia and she replied

that it was possible that some of them had “*the fibromyalgic component*”, because surgical interventions often cause the patients psychopathological problems.

*Doctor B.’s conception of fibromyalgic syndrome is that of a purely psychological issue which may occur in patients who had traumatic interventions such as an operation. The term “fibromyalgic component” came out several times when speaking with doctors. This definition looks at fibromyalgia as a psychopathological issue which may accompany an organic issue, such as a disease: in this sense, this “component” has to be taken in account because it may worsen the patient’s perception of her condition. At the same time, this label neglects that FMS is a disease in its own right since it does not conceive of it as a rheumatic disorder and not even as a mental condition.*

*The conception of FMS as a psychopathological problem recurred quite often in the physicians’ talks. Sometimes, when speaking privately or between them, the term fibromyalgic was clearly employed as a metaphor of person with mental issues or, more generally, to define a person with mood issues.*

The same day, I witnessed to another consult with a fibromyalgic patient, a 50 years old woman. FMS started when she was 25, a couple of years after her first childbirth. She was admitted to a neurologic clinic for her widespread pains; here, some tests were run but the results were all negative, so she was discharged without *a diagnosis*. In the patient’s opinion, this was because at that time physicians were not used to diagnose FMS. At any rate, the pain continued and spread in all her body; she tried different treatments but none of them was beneficial. Her condition

got worse after the second pregnancy (the patient had three childbirths and an abortion): her first delivery was problematic, the child risked a brain damage but then everything went right. However, her daughter had frequent headaches and faintings which, in the patient's opinion, indicated that she had suffered of a brain damage during the intervention. The second child was fine, while the last one had a minor cognitive impairment.

Going through the anamnesis of the patient, interventions, consultations and health issues seemed to multiply and at a certain point it became very difficult for me to follow the consult. This was also because the patient's narration was quite confused and she often said to be sorry because she could not explain very well herself since she felt very nervous. The Doctor kept on listening and sometimes remarked on the huge quantity of exams and analyses done by the patient as to suggest that they were too many.

Even though she never had improvements in her health condition, there was a turning point when she decided to quit the gp who had followed her for 25 years and consulting a neuropsychiatrist working in the Mental Health Service of her hometown. The patient went there for a depression, treated with fluoxetine. After a while, she started also having panick attacks and a widespread anxiety. The patient saw this problems as due to the tragic events happened in her life and to her attitude of "looking for perfection" and the deep sadness following the disillusion of her expectations. The patient listed then *the drugs* that she was currently taking: i) Trittico (trazodone), a common antidepressant, ii) Lyrica (pregabalin) and iii) Eflexor

(venlafaxine chloridate), two medications often employed in the treatment of FMS, iv) Xanax (alprazolam), a benzodiazepine used to treat panick attacks and agoraphobia, v) Lorazepam, vi) En (delorazepam) for the anxiety, vii) Azomyr (desloratadine) and an antihistaminic for her allergies. Notwithstanding the impressive pharmacological apparatus, the patient still felt very bad: she had frequent allergic reactions, paresthesias and her pain was so bad that sometimes she woke up in the night crying.

*Even if this patient's situation represents an extreme case, overmedication is very common in FMS patients. These patients take many drugs, even if, usually, not at the same time. As I will stress the next section, fibromyalgic patients often try several treatments, particularly pharmacologic ones, in the attempt to find a cure for their symptoms. Nevertheless, most of the times, even if a drug is beneficial for a period, the effect does not last long or the patient has to quit it because of the severe collateral effects which antidepressants and anxiolitics bring about.*

The patient told us also that she had claimed for the disability pension, but she could not get it because "FMS is not recognized as a disease." This, in the patient's view, was also the reason why she could not find a job: her condition and her age made very difficult to find a work and, without the disability certificate, the Unemployment Office could not find anything suitable for her. Previously, she had worked in different places as cleaning lady. Every time she saw a doctor, she was told to change job because it was not good for her health condition, but she could not leave because she was the only person working in the family.

The Doctor pursued the physical examination and even if some tender points resulted painful at the palpation, the patient seemed worried because she did not feel as much pain as usual. In the meanwhile, the patient kept telling about her problems and the different treatments that she had done during the years. The depression and the panick attacks were recurrent topics in her narration but these problems, in her perspective, were just “normal reactions to her condition”.

In the conclusion of this very long consultation (about 1hour and a half), the patient asked for medical advice to Doctor R. who stated that something could be done, but it was not possible to find an ultimate cure. The patient seemed to understand and claimed: “Please, tell me what I have to do. With these feelings that I have, I would change my blood and my brain, if I could.” The doctor confirmed the pharmacological therapy adding the Efferalgan (paracetamol) to control the pain, and suggested the patient to lose weight and to do physical activity, preferably outdoor. The patient seemed partially satisfied but still she wanted to know if there were other tests that she could do. While leaving, the patient thanked the Doctor because at least she had told her that she did *have something*.

This patient’s consultation was exhausting so I took a break. When I came back, the Doctor was visiting a young arthritic girl. At the end of the consult, Doctor R. made me notice how the variability in the perception of one’s own health status, by explicitly referring to the different approaches to their own health status between the girl and the patient visited before.

*That day's consult stimulated many reflections. It was clear that even if the patient had a FMS, this was only one of the multiple issues that were negatively affecting her health and, more generally, her life. In addition to her troublesome health situation, the patient had no idea of what to do to feel better. Her suffering was overwhelming and it was very difficult to figure out, in the vicious circle of pain, distress, psychological issues and life problems, which was the cause. In the chaotic narration of her condition, health problems and life troubles were hardly distinguishable. Furthermore, several medical consultations, exams, analyses and drugs had only worsened her affliction. Notwithstanding this, the woman was still looking for a medical solution to her distress. At the end of the consultation, the patient told us that the reason why she had left her gp was that she wanted to take out some drugs, but the patient was worried to do so, therefore she went to see another doctor.*

*The diagnosis of fibromyalgia seemed to have somehow helped the patient by giving a name to her suffering, and therefore, by recognizing that she had something. At the same time, though, this diagnosis, confirmed by Doctor R., had not led to any significant change in the patient's situation: the treatment remained almost the same and the patient was told to keep on going to the Mental Health Service. Some advices were given to the patient: stay outside, do physical activities, stop pursuing medical investigations and, more generally, looking for something organically wrong in you.*

*As in other cases, I felt as I was observing a psychosocial consultation where the patient spoke profusely, the physician listened, and, in the end, some suggestions on*



*how to change the patient's approach to her condition were given. Of course, Doctor R. did not pursue an actual psychiatric consult, but the unspoken discourse underlying that encounter was more or less this: I know you are suffering, but, as a rheumatologist, I cannot do anything for you beside trying to help you to control your pain. This appeared paradoxical to me: the patient had a FMS diagnosis, confirmed by the Doctor, which however did not affect in any effective way the situation. So, I asked to myself, was it worth to diagnose fibromyalgia when it was not possible to give also a cure for it?<sup>106</sup>*

The following day, I went to the clinic in the afternoon, because Doctor R. had told me that she had to visit a potential fibromyalgic patient. The patient was a Pakistan young woman. While her gp had told her that she did not have anything, Doctor M. had diagnosed her fibromyalgia and had asked her to run some tests.

Since 2009, she had pain all over her body which she defined as “heavy like iron”. The pains made her “crazy” and thwarted her from doing any activity, at home and at work. Doctor R. went out to take her medical chart and we started talking. Her pains were widespread and highly changeable in location; usually, they worsened after labor, which anyway was unavoidable because of her job. The woman worked in a school canteen and she often had to lift heavy boxes. The first time she had an attack, it was the day after a long day of work when she had lifted some water boxes. While the doctor was still outside, the patient asked me about FMS, what it was, if

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<sup>106</sup> During my observation, I had the occasion to meet a patient who healed from FMS. The patient had a RA diagnosis in addition to that of fibromyalgia. In this case, the treatment of the primary condition, RA, had entailed also the “disappearing” of fibromyalgia

she could have it and if a diagnosis of fibromyalgia could be a reason to claim for disability. Her pains had forced her to stay at home for many days in the last year, and her boss had told her that he would have fired her if the situation hadn't have changed. After a while, Doctor R. came back and, speaking with the sister who was accompanying the patient, we were informed of the fact that in her family there was a history of rheumatic problems. The Doctor started therefore examining more accurately the huge exam's dossier and discovered that the FMRI run few time before showed the presence of a bad inflammation in the patient's left hip, which was also where she felt more the pain. The family history and this exam's finding led the Doctor to the conclusion that the patient had not fibromyalgia but a seronegative spondylo-arthritis.

*In this case, the presence of multiple and widespread pains not accounted for by a detectable pathological process had entailed a diagnosis of FMS. In order to confirm it, the Doctor had asked the patient to run another test which previously had not be done. Seronegative spondylo-arthritis is a label defining a group of several inflammatory arthritis which usually affect individuals with a genetic predisposition characterized by the absence of the rheumatoid factor, which is an autoantibody and a criterion to diagnose Rheumatoid Arthritis.*

*As in the majority of the cases, FMS diagnosis was made on the basis of the exclusion of other morbid processes accounting for the patient's pain. FMRI had showed instead the presence of an inflammatory process, and the first diagnostic*

*hypothesis had therefore fallen because there was something organic wrong accounting for the patient's symptoms.*

*If FMS is often diagnosed when no organic findings account for the patient's symptomatology, more often fibromyalgia accompanies other conditions. This is what in medical language is defined as secondary fibromyalgia, i.e. the patient's medical condition is primarily defined by a rheumatic disease which is characterized also by a fibromyalgic symptomatology, as in the next case presented.*

The patient was a 55 years old woman with a diagnosis of osteoporosis and undifferentiated connective tissue disease (UCTD), in addition to FMS.

At the beginning of the encounter, the patient told Doctor M. that she had stopped taking some of the drugs prescribed because, in her opinion, they were too many. Among these, the Plaquenil (hydroxycloquine sulfate) gave her allergic reactions and the Tachidol (paracetamol and codeine) had no beneficial effects and caused her confusion and vertigos. The patient argued, "I am fibromyalgic so I have pain all over". The patient's resignation to her condition contrasted with the history told by her medical chart, indicating that she had gone to see a neurologist and run many tests, all negative. "I am a mysterious patient", the woman commented. However, the patient asked the Doctor her opinion about her constant pain. Doctor M. confirmed that it was FMS' pain. The patient seemed puzzled and asked the doctor if there was a cure for it and the reply was that the only treatment available were painkillers and antidepressants, the latter, *not because of the depression but for the pain*. The consultation went on and the patient and the doctor kept on discussing about the

patient's decision to quit the prescribed pharmacological treatment. The patient was irremovable: she did not want to take those drugs anymore but she wanted to find an alternative cure. Some friends had told her about a treatment with placenta, and she wanted to try it. The doctor kept on saying that she had to change her mind because the drugs prescribed were effective for her pathology, while the effects of placenta had never been scientifically demonstrated. The patient went also to see a physiotherapist who advised her to do gymnastic for her stiffness. In the doctor's view, this could help since this symptom, due to her connective tissues disease, could worsen the pain. The patient's view was different: "I don't know if I am so rigid because of FMS or if it belongs to my being." Doctor M. replied: "It is part of your person, and we, clinicians, read it as FMS; it is originated from how you approach things, how you want to control them..." The Doctor framed then the patient's condition as due to an altered sensitization decreasing her pain threshold which became worse during the night because when sleeping the brain was more active. "People have troubles at sleeping because they are not able to make their brain rest."

*This was the first time I heard a doctor explaining a FMS patient her condition by referring to the central sensitization framework. In this case, the patient had taken medical decisions on her own which could cause severe consequences. During the consult, fibromyalgia was defined in different ways: while the patient seemed quite aware of her condition (I have FMS so I have pain all over), at the same time, she was unsatisfied by the answers provided by the biomedical discourse and she was clearly still looking for a clarification; the Doctor, in the attempt to achieve the*

*patient's compliance and make her take the medications for the UCTD, provided her with different explanations of how FMS affected her condition: the pain was due to FMS, it could be treated with analgesics and antidepressants, and even the way she felt, her stiffness, was attributable to fibromyalgia. These symptoms were, at the same time, also expressions of the patient's being: these issues were indeed a bodily feature as well as a way in which the patient approached life in general. Finally, this whole distressful condition could be scientifically ascribable to a pathological dysfunction causing the patient an altered perception of symptoms such as pain.*

*Fibromyalgia is, as it has been highlighted, a complex condition. Complexity refers to the fact that pathological features characterizing it are not restricted to the organic domain and not even to the psychological one; moreover, these aspects, deeply intertwined, are also mutually reinforcing. FMS is indeed pharmacologically treated with medications which affect physiological as well as psychological processes. Nevertheless, such an articulate approach lacks in the medical system's organization, so that rheumatologists have to deal with patients with several distressing problems, including mood issues, which they feel that do not belong to their competence. At the same time, patients have symptoms usually treated in Rheumatology, such as pain in the muscles, for which they search therefore an organic explanation, which is left unsatisfied. In this sense, the hypothesis put forward in the conclusion of the previous chapter, i.e. that dualism persists in biomedicine, is confirmed. However, as suggested, the dualistic divide between mind and body, between psychological and organic conditions, appears to lie not in the*

*actors' minds, but in the concrete structure in which they act which reinforces such a dichotomy. An interesting aspect of this issue concerns patients' perspective on their condition and on its multiple and various symptomatology. While the presence of chronic and widespread pain is usually seen by the patients as a manifestation of fibromyalgia, other symptoms recognized in the scientific literature as characterizing FMS, such as the stiffness, the fatigue and the cognitive and mood issues, are not always recognized by the patients as connected to their condition such as pain does. In the last consult, the patient did not understand if her stiffness was due to her FMS or if this belonged to her being, i.e. she was a rigid person.*

*The predominance of pain on the other symptomatological manifestations of fibromyalgia is retraceable, at the same time, in fibromyalgia diagnostic criteria, which make this condition a rheumatologic problem because of the localization of pain, in the physicians' approach which mainly focus on the pain and its control, and in the patients' perspective, who usually conceive of their other problems as a direct consequence of the presence of the pain.*

A couple of days later, I went in the consultation room with Doctor S. who had a patient at her first-visit. The woman, in her 50es, told us that she stayed for many years in a private clinic which at a certain point closed so she started wandering in different structures, but nobody could ever find the cause of her pain.

In 2007, the patient was diagnosed RA, treated with different drugs because every time she had to change the therapy because of intolerances. The patient listed all the prescribed medicaments among which two antidepressants, even if she did not take

them. She told us that her gp diagnosed her *a depressive syndrome* but she did not agree and ascribed instead her problems to the overwhelming pain: “When you wake up every day with pains it is hard not to be depressed...” She was sent to Rheumatology by her gp because “she did not know what to do anymore”. During the consult, *the dissatisfaction of the patient* with the treatments proposed during the years emerged clearly: she refused to follow the gp’s prescription and also admitted to have autonomously changed her pharmacological therapy by searching on the Internet alternative treatment. Moreover, by looking at her analyses’ dossier, we found out that she had seen different specialists and done several exams, *all negative*. The Doctor pursued the physical examination and as soon as she pressed on the patient’s back, the woman started *crying*. Doctor S. looked at me and said: “She defenetely has a fibromyalgic component.”

When the Doctor went out to photocopy the patient’s analyses, the woman started telling me about the depression: her gp told her that it could have been caused by the pain, and she had told her to take Xanax to relax the muscles and ameliorate her sleep, but she was not convinced. In the patient’s view, the depression was normal: “I have realized that when I am quiet, I do not have bad thoughts, I do not think about my dad, I do not think about my mum who keeps on being hospitalized and so on...”

At the end of the consultation, I read on the computer the doctor’s report saying that the patient had RA and osteoporosis, but not FMS. When the patient left the room, I asked the Doctor why she did not report fibromyalgia. The reply was that even if there was a fibromyalgic component, the most relevant thing was the RA and

maybe, treating this condition, also the FMS could have improved. Also, the Doctor added: "if she refuses to talk about her depression, it is difficult to help her." I told her that the patient had instead spoken with me about this and the doctor's reply was: "Well, you are here for this, aren't you?"

*Even if I introduced myself to the doctors of the clinic as a PhD student in Philosophy, aiming at observing the clinical encounters with fibromyalgic patients, more than once physicians referred to me as a psychologist. The reasons of this misunderstanding may be many: among these, an underlying conception that if one wants to study FMS, she has to be a psychologist, further witnesses for a psychological view of fibromyalgic syndrome; moreover, another source of confusion may be due to the common idea that the object of study of philosophy does not differ so much from that of psychology. Beside these issues, I think that the responsibility was also mine, i.e., I had not properly communicated my positioning as a researcher in that place to my informants. Moreover, while the majority of the clinicians saw me as a psychologist, most of patients believed that I was a doctor. The reason of this was clear: I was constantly wearing a white coat kindly borrowed me by Doctor M. and I was standing behind the desk with the other doctors. Even if this made me feel at first a bit uncomfortable, also because sometimes patients asked me about medical issues, at a certain point I concluded that my camouflaging was helpful for my research by allowing me to observe and participate to the interactions without drawing too much attention on me. At the same time, though, the misunderstanding about my positioning could also be due to the fact that it is quite uncommon for a*



*philosopher to do a fieldwork research, which is instead a typical anthropological or sociological method of enquiry. In this sense, I wondered: does the research I am doing here turn me into an anthropologist or a sociologist or is there anything worth for a philosopher to find out in the field? When I chose to conduct a fieldwork research, my aim was to confront my theoretical analyses with an enquiry on how actually things were in the practice. Observing clinical interactions as well as talking to doctors and patients has indeed profoundly marked my research. In particular, I believe that without the reflections brought about by my observation, my analysis of the ways in which an entity such as FMS is defined as a pathological condition cannot but consider the ways in which this process takes place in the clinical practice, where theories and conceptions are applied and often reshaped on the basis of the different situations. A more in-depth reflection on this issue will be presented in the Conclusion of the dissertation.*

After some days without seeing a fibromyalgic patient, while I was in the consultation room with Doctor G., a woman came in claiming: "I am 44 but I have the pains an old woman has." The patient's pains started 4 years before, in the legs, in the arms and in the hands. After some time, she started also feeling very tired, having paresthesias and even if she slept during the night, she woke up "more tired than the evening before." All the analyses that she had done were negative. As the physical examination began, the patient asked Doctor G. if she could hear that her heart was racing. Doctor G. looked at me and said: "This is one of your patients." The physical exam showed the presence of 16 painful tender points at the digital

pressure. The Doctor concluded that the patient had a FMS, i.e. a muscular pain lasting for more than three months. The therapy, Doctor G. said, “is based on painkillers. My advice is to start with Paracetamol 1000 and see how it goes. Moreover, you are very tense so you should do a therapy to relax the muscles. If the blood test prescribed is negative, your therapy is confirmed.”

When the patient left the room, Doctor G. stated: “This was an atypical fibromyalgic patient because she did not complain so much.”

*Doctor G.’s definition of fibromyalgic syndrome as a “muscular pain lasting for more than 3 months” recalls the standard definition of chronic pain<sup>107</sup>. In this case, fibromyalgic syndrome appears as an a-specific chronic pain condition, among the others. Consequently, the therapy is based on paracetamol which is an analgesics widely prescribed for pain symptomatology, without addressing FMS with a specific treatment.*

*Doctor G. comment on the fact that the patient was an “atypical fibromyalgic” since she did not complain a lot, is another aspect characterizing physicians’ view of these patients. A consult with a fibromyalgic patient represents for many doctors an hassle: the two painful symptoms characterizing fibromyalgia, i.e. allodynia and hyperalgesia, lead these patients to have excruciating pain everywhere in their bodies so that every movement implies a lament; moreover, the stories of these patients are strongly painful and listening to them may be consequently wearing. Even though the extensive distress and the corresponding complaining of these patients are*

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<sup>107</sup> See Chapter 3 *Pathological pain: chronic pain as a disease*

*accountable for by the scientific framing of fibromyalgia, i.e. FMS means having pain-all-over, still the overwhelming suffering of these patients, and its expression, is sometimes seen by the physicians as exaggerated. In several occasions, doctors have underlined how disproportionate was these patients' complaining in comparison to that of other patients having "bad" conditions, who anyway controlled more themselves. The fact that sometimes chronic pain patients are seen as "making-a-mountain-out-of-a-molehill" was indicated by Jackson as one of the delegitimation processes affecting these patients, consequent to the liminal status of chronic pain between body and mind. (See 3.3.3. The problematic status of chronic pain as a disease) The fact that FMS' pain is not accounted for by a detectable underlying morbid process, such as for RA leads, by the way of the equation non-organic = psychogenic, to a stigmatization of these sufferers because their complains are seen as somehow unmotivated. Furthermore, such a conception, i.e. that "real" pain is the pain related to an organic pathology, reconfirms the persistence of a conceptualization of chronic pain not as a disease in itself, but as the manifestation of an underlying pathology.*

The same day, while I was with Doctor G., we saw another fibromyalgic patient. The woman was a middle-age school teacher. Her diagnosis was RA and Psoriatic Arthritis, plus FMS. The predominant symptom was a severe and burning pain, above all in the lower parts of her body, but she also had severe limitations due to the stiffness and she also had troubles at sleeping. The patient's functional limitation was extensive so that she had stopped driving, she had troubles at work because the

cortisone made her feel asleep and confused, and it often happened her to fall because she felt dizzy. Her cognitive symptoms, in addition to the fact that her mother had Parkinson, brought her to run many neurological tests, but the results were all negative.

At the physical examination, she had 18 painful tender points. Every time the Doctor made pressure on her body, the woman got tense and, at a certain point, Doctor G. told the other doctor that it was not possible to understand whether and where the patient was painful, because she was hurting everywhere.

*Pain is the predominant symptom in FMS, as in the majority of rheumatic conditions. However, the painful symptomatology may widely vary and, consequently, the diagnosis: fibromyalgia-related pain diverges from the inflammatory pain characterizing conditions such as RA or spondilo-arthritis, while a mechanical pain, usually occurring in association to specific gestures or postures, may indicate a joint's alteration due to a degenerative or to an inflammatory condition.*

*The physical examination is a crucial part of Rheumatology consultation: here, the physician scans the patient's body in search for painful areas and tries to assess her functional limitation. When the patient reacts to the physician's touch by complaining pain, this means something. However, having pain does not entail anything per se in a diagnostic perspective, and the physician has to understand what kind of pain the patient has: where it is located (in one or more body parts, it is changeable and/or widespread), its temporal dimensions (it is acute or chronic, flickering or throbbing, it*

*occurs in association to specific movements or postures) and, more generally, how it is described by the patients (burning, radiating, piercing, but also hurting, heavy, exhausting, annoying, fearful, vicious, and so on).<sup>108</sup> All these information can be gathered only by asking the patient how her pain feels like. The patient's indications are confronted then with the outcomes of the physical exam. Sometimes, the findings are coincident so the doctor has a quite clear picture of the patient's situation, coupled with the anamnesis and the results of the more recent analyses. But it also may happen that there is no coincidence between what the patient tells, her tests' results and the physical examination's outcomes.*

*In the last patient's case, the doctor was trying to evaluate the extent of the damages of the arthritis. The presence of FMS-related pain, the typical pain-all-over, was an obstacle to the pursuing of this investigation because the patient's pain, instead of being a precise radar to detect where the inflammatory process was active, affected all her body. In this case, the pain was an untrustworthy tool for the diagnosis because it was widespread and, therefore, not related to a precise body system. As already highlighted, in the biomedical framework the localization of pain remains a crucial issue; such a view, witnessing for the persistence of a conception of pain as a symptom of disease instead of as a disease in itself, substantiates also the collocation of fibromyalgia in the rheumatologic domain. In this sense, the*

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<sup>108</sup> The mentioned adjectives have been employed by the patients during the consults I have witnessed to. At the same time, they are also listed in the McGill Pain Questionnaire, the well-recognised tool to assess the patient's pain. (Mc Gill Pain Questionnaire is available online at [www.gem-beta.org/public/DownloadMeasure.aspx?mid=1348](http://www.gem-beta.org/public/DownloadMeasure.aspx?mid=1348))

*problematic status of FMS as a disease is the direct consequence of a wider troublesome acknowledgment of pain itself as a pathological phenomenon.*

*Moreover, the co-occurrence of fibromyalgic symptomatology with the manifestations of another rheumatic condition may entail further problems in the diagnostic process because patients, particularly fibromyalgic ones, have usually seen many specialists, who may have wrongfully ascribed the patient's symptoms to fibromyalgia while other health problems were affecting the patient. The following case is emblematic in this regard.*

The patient was a middle-age Moroccan woman, diagnosed with LES. She was treated with Medrol (Metilpredisonone) and Plaquenil, but she was still having a lot of pain, particularly under her breast. She had gone to see a lung specialist who had discovered a pleuric spill, which anyway could not account for her pain. She had run many scans but the results were all negative. At the physical examination, the patient presented severe difficulties at breathing that the doctors clearly did not know how to interpret. In the patient's view, this sensation of oppression was related to her pain: when she felt pain, she could not breath properly and if she tried to breath, her pain worsened. Moreover, her blood test showed some abnormal results leading Doctor G. to doubt of the diagnostic conclusions of the doctors who had previously seen the patient, i.e. that she only had FMS. In addition to the pleuric spill and the blood tests' results, the Doctor had detected also inflammatory manifestations. The Doctor told therefore the patient to do a cardiac ultrasound which, if negative, would have

indicated that she had only FMS and that her LES was stable. If the outcomes had showed instead something, then they would have changed the therapy.

The patient's husband, who had accompanied her, asked the Doctor if she could identify what was causing her wife so much pain and Doctor G. replied that they had to figure out if the pain was solely muscular or if there was also a damage related to the lungs or the heart because LES could affect also that system.

After a couple of weeks without seeing fibromyalgic patients, while I was in the consultation room with Doctor C., a woman came with a diagnosis of FMS. The patient's medical chart indicated that she had epilepsy -she took Gardendale (fenobarbital) for it-, FMS and an arthrosis. The rheumatologist who had diagnosed her fibromyalgia had prescribed her paroxetine and had referred the patient to a neurologist to evaluate also the treatment with Xeristar (duloxetine). However, the woman told a different story: paroxetine had been prescribed her for a nervous breakdown, and even though FMS diagnosis was reported in her chart, she never said to have it. Moreover, we learned about the fact that the patient had seen several specialists but, in her opinion, no one of them had told her what she was suffering from. Also, the patient kept on drawing our attention on the last blood test that she had taken, indicating that one result was abnormal. The Doctor did not pay much attention to that and pursued the physical examination; the woman's reaction to the tender points' pressure was quite tempered, and the Doctor concluded that this criterion had not been satisfied.

While the doctor was visiting her, the patient kept on telling us about her medical and life history: she had pain-all-over, irritable bowel syndrome and she often felt very cold even if the temperature was hot; her condition had caused her the loss of the job and she spent most of the time at home with her parents, 100 percent disabled, with whom she never have had a good relationship.

The Doctor advised the patient to figure out if all the medications that she was taking were effective, by suggesting that they were too many. The patient claimed in response that the half of the doctors had told her to quit with some drugs, while the other half did not agree. Therefore, the woman added, “I am so afraid to take off any of them, I have no idea on what could happen then.”

Doctor C. wrote the conclusive medical report indicating that the woman had a painful shoulder, that she was in treatment for epilepsy and that she presented some signs of fibrositis<sup>109</sup>.

As the patient got out, I and Doctor C. spoke about the case. The physician’s opinion was that the FMS diagnosis made by the other doctor was aimed at prescribing the Duloxetine for the patient’s mood issues. “If I lived as this patient does, I would have a depression too”, he added.

*In the clinical consultations, the relationship between fibromyalgia and depression appears much more complicated than presented in the literature. Throughout the course of my dissertation, I have stressed repeatedly the problematic acknowledgment in biomedicine of the link between chronic pain and mental*

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<sup>109</sup> Fibrositis is the old label of fibromyalgia. See 4.1.2 A brief history of FMS



*disorders, in particular, depression. If nowadays the most shared view in the sciences is that these conditions are mutually influencing –and therefore there is no linear cause and effect relationship- and even the underlying morbid process is the same, still this matter has to be tackled in relation to the potential stigma following a diagnosis of depression. As for the “cause-issue”, my perspective on this matter has widely changed after my observation. First of all, as already mentioned, the overwhelming gap I was looking for in the physicians’ discourses between mental and organic disorders does not lie in an a-priori distinction between mind and body underlying physicians’ conceptions. Secondly, and more surprisingly, the patients’ aversion towards depression has revealed troublesome not because of a moral issue, that of being seen as depressed person, but because this could lead the physicians to ignore the “reality” of the patient’ symptoms, and therefore, stop them searching for a cause. In this sense, the problematic acknowledgment of chronic pain, instead of being a theoretical issue consequent to an explanatory framework unable to appreciate the multifaceted character of pain and, more generally, of disease, proves again to be a practical matter, shared by patients and physicians: the incapacity to name, to explain, and therefore, to cure the overwhelming suffering of these patients. As Illich argues (Illich, 1975), today pain is a medical problem, i.e., pain, as we know it, is the product of a specific knowledge, the biomedical one. The power of biomedicine on pain is self-sustaining: pain belongs to medical competence because medicine has showed to some ability to cure it. But what if this process is interrupted, what if, as in the case of fibromyalgia, biomedicine names the patient’s*

*distress, FMS, but then it is not able to treat it? Does it mean that there was a mistake already in labeling that distress fibromyalgia, by making it therefore a medical competence? And if it is so, is it possible to come back?*

“I have a painful clinical history”, began the patient. Her medical chart reported that was affected by FMS, Depressive Syndrome and asthma. “If I tell you how I live, you will understand why I am depressed.” The last specialist who had visited the patient was a gynecologist, for a problem with the uterus. The doctor had told her to run an FMRI, but the patient kept on delaying it because she was claustrophobic and the FMRI machine scared her. “I’ve never felt good. This morning I wanted to commit suicide while yesterday I felt great. Today, my leg doesn’t want to obey while three days ago I had a terrible cystitis.”

The patient had been sent to Rheumatology from the First Aid, where she went for a pain in her leg. She reported that when the doctor saw her chart, she sent her away immediately because of her FMS diagnosis. “They say that I am an hypochondriac”.

The Doctor asked the patient if she was in treatment for her depression and the patient started telling us about it and showed us a picture of her dated back to a couple of years before. “You see, I cannot even recognize myself. I have lost my husband so I got an awful depression. As I was starting to improve, I met a man who abused me... I also have asthma, and a thyroid problem. I wanted them to take off my uterus, so at least I could have solved one of my problems...”

Doctor R. read the patient’s medical chart with her last diagnosis: “The patient presents a complex multi-pathological clinical picture consequent to emotional

problems.” After the physical examination, showing no significant results, the Doctor attempted to discharge the patient who instead appeared not willing to do so. “Doctor, how is it possible that I feel so bad, I mean, which is the cause?” The Doctor replied that there were different factors at play which contributed to her general distress. The patient asked further: “do you agree with my gp, is fibromyalgia the cause?” and the Doctor said yes. Doctor R. writes down further: “From a rheumatologic point of view, the patient has a FMS, not secondary to another condition.” And then, pointing towards the patient, she added: “The treatment is based on analgesics and antidepressants. I therefore send back the patient to the psychiatrists and neurologists treating her for years.” The patient kept quiet for a second and asked the Doctor: “Do you think that I feel bad again because I quit the antidepressants?”. Doctor R. replied that it was possible. Anyway, “there is nothing wrong with you, in a rheumatologic perspective.”

*As remarked in the section devoted to the comorbidity between chronic pain and depression (3.2.6 Chronic pain and depression: a digression), the actual biomedical framework does not allow an integrated management of persistent pain and the related mood issues leading to a disjunctive approach in which depression and chronic pain are instead mutually exclusive.*

*In the last case presented, the patient had already a diagnosis of depression, handled by psychiatrists and neurologists. The prominent depressive state of the patient had entailed a definition of her condition as wholly psychological so that the recognition of the presence of pain and, more generally, of a fibromyalgic syndrome*

*did not entail a rheumatological management of her condition since, in this perspective, there was nothing wrong.*

The last fibromyalgic patient I saw was a man, the only one I met during my observation. The patient complained of persistent, distressing pain all over his body, particularly in his right hand. “Sometimes, during the night, it hurts so much that I wake up and cry.” The patient complained also cognitive symptoms such as dizziness and confusion, in addition to the fatigue. He had a Psoriatic Arthritis diagnosis plus FMS and diabetes. The Doctor made an ultrasound to assess the presence of an inflammatory process in his shoulders and hands which took quite a long time because the patient was hurting so much that he could not even move. The pharmacological therapy was tramadol and methotrexate, in addition to other drugs for the diabetes. The scan detected an inflammation in the left shoulder and in one finger so the Doctor pursued a cortisone seepage. After a while, the patient claimed to feel better, even if when he had to dress up, he kept on groaning very loud. Before leaving, he turned to us and said: “before I got sick, I had no idea of what it meant to feel bad. Now I know that having pain makes you want to die.”

#### *4.2.3 Conclusive remarks: how many fibromyalgic syndrome(s)?*

In this section, I have presented and discussed the findings of my observation of the interactions between rheumatologists and fibromyalgic patients in a local clinic. Furthermore, a self-reflexive analysis of the way in which I have conducted this research has been reported and it will be further developed and related to the theoretical and historical reflections I have been presenting in my work.

My research question, how does fibromyalgia emerge in the clinical practice? finds a reply in the acknowledgment that what biomedical knowledge labels as fibromyalgia is not a single object, but many. Fibromyalgia is, in some cases, a pathological condition, which may be a complex psychophysiological morbid entity or a purely psychological disorder. Furthermore, FMS may be merely a component, accompanying some rheumatic disorders and contributing to the worsening of the patient's own health status perception. Fibromyalgia may also represent an attitude, showed by some patients and which is recognizable on the basis of some indicators which, in turn, constitute its diagnostic criteria but also by other features which do not specifically pertain to the Rheumatology field. Finally, fibromyalgia is a name given to a profound distress presented by some patients, which is sometimes accompanied also by a depression' diagnosis.

My investigation of fibromyalgia in the clinical practice moves from the hypothesis that it is not my job showing if fibromyalgia exists or not, because FMS is retraceable, in my view, only in a specific site, i.e. biomedical knowledge; this is a powerful system of knowledge including doctors' as well as patients' perspectives, conceptualizations, tools, practices and the same objects of this knowledge. In this sense, it is possible to say that fibromyalgia exists as multiple objects in the biomedical knowledge. FMS is generally recognized as a pathological state, even if an ultimate understanding of it as a specific clinical entity remains debated.

In the following section, I will focus on fibromyalgic syndrome by referring to the patients, whose perspectives still remain to be tackled. I want to stress that this

analysis is not aimed at investigating patients' perceptions of pain and not even patients' experiences of illness as if they were lying outside the picture. Quite the contrary, fibromyalgic patients do actively participate to the definition of fibromyalgia as the object of biomedical knowledge. Moreover, the contested status of FMS a disease, forces these patients more than others to contribute to the acknowledgment of the pathological status of their condition. This, of course, is not a simple thing, since they are concretely dealing with fibromyalgia by suffering of it. It is precisely because of the particular positioning of the patients in relation to fibromyalgia, i.e. their participating to the definition of this entity as well as being affected by it, that the enquiry has been pursued by using different methods of investigations and, particularly, the photographic tool. The aim was to get as close as possible to the patients' daily dealing with this condition, by analyzing also aspects which are usually difficult to communicate through verbal language.

### *4.3 The pains of living with fibromyalgia*

#### *4.3.1 Introduction*

This sections looks at fibromyalgia as a pathological condition which defines and is defined also by the experiences of fibromyalgic patients; in the following pages, the findings of an enquiry on the patients' experiences of illness will be presented. As already anticipated, this part of my investigation aims at giving voice to fibromyalgia sufferers; at the same time, though, this enquiry does not intend to be solely a report of the ways in which fibromyalgia affects the sufferers' lives, but it aspires at shedding further light on the object of research, i.e. how fibromyalgia comes to be

defined as a disease. In the patients' accounts of their daily living with FMS, unravelled through the employment of photography as a research tool, such crucial issues as chronic pain's causation, the boundaries between mental and physical pain, and the definition of a chronic pain as a disease, emerge as part of the individual experiences of the sufferers as well as pivotal features characterizing the biomedical condition labelled fibromyalgic syndrome.

#### *4.3.2 "Progetto Benessere": reshaping the research*

I met the fibromyalgic sufferers who have then become my informants during the development of a therapeutic rehabilitative program for fibromyalgia, run in a spa not far from Bologna, *Progetto Benessere* (Wellness Project). This therapeutic program, organized by A.M.R.E.R.<sup>110</sup>, a local patients' association, in collaboration with the University of Ferrara and Riolo Terme spa, aimed at ameliorating pain' symptomatology, through the employment of complementary therapies to the pharmacological one, such as physical therapies, relaxation, massages and osteopathic treatments<sup>111</sup>.

At the beginning, my idea was to investigate how fibromyalgic syndrome was dealt with and defined in a different therapeutic site from the traditional one, i.e. the

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<sup>110</sup> Emilia Romagna region rheumatic patients' association

<sup>111</sup> Progetto Benessere is, at the same time, a therapeutic-rehabilitative program for the management of fibromyalgic syndrome as well as a pilot project whose efficacy is evaluated by the rheumatologic Unit of the University of Ferrara on the basis of: i) the comparison of the outcomes of an initial and final rheumatologic visit (tender points' and VAS scale for pain assessment) and the surveys of three questionnaires that patients have to fill in at the beginning of the program, then after three months and after six: the SF36 (Short Form Health Survey, the FIQ (Fibromyalgia Impact Questionnaire and the FACIT (Functional Assessment of Chronic Illness Therapy)

Rheumatology Division, where I had already conducted a participant observation. Moreover, I wanted to interview the patients participating to the project in order to elicit accounts of their experiences of illness. After a couple of days at Riolo, though, I realized that I had to reframe the focus and, consequently, the methodological approach to that part of my research. First of all, my initial idea, that of conducting an investigation on an alternative therapeutic management of FMS which could be later compared with the observation run in S.Orsola, was unattainable, for structural and technical reasons. While at S.Orsola I had almost uniquely observed clinical interactions, Progetto Benessere consisted in the development of several therapies. Furthermore, even if, according to the majority of the patients involved, Progetto Benessere had showed to be beneficial, this period represented a parenthesis in a wider and permanent biomedical management of their condition. In this sense, I concluded that although some interesting analyses could be pursued on a different management of fibromyalgia, these findings could not be coupled with the outcomes of my previous observation. In addition, practical matters forced me to redefine my object of research, by choosing between conducting a participant observation on the whole project or focusing on the patients and their experiences of illness. The project, lasting a total of ten days, was structured in three hours of everyday activities, conducted by the patients individually or together, after which, most of them left the structure. During the development of the project, I followed the patients' initial consultations and some activities, but for the majority of the time I spent my time at Riolo talking to the patients. By listening to and speaking informally with the patients



during the first two days of activities at Riolo, I felt that, by focusing on the patients and their narratives, I could tackle those aspects that I aimed at investigating. In the patients' accounts of their everyday dealing with FMS, the issues I had focused until then, such as chronic pain's causation, the boundaries between mental and physical pains and those between organic and psychological approaches, and the acknowledgment of fibromyalgia as a disease, were constantly tackled.

In the next pages, I will briefly report a conversation with some of the patients which have been later involved in the photographic research project. Even though the medical histories of these patients presented some differences, a feature shared by all of them was the fact that they had been diagnosed with fibromyalgia for more than ten years and they were medicalized for even longer. Beside the fact that most of them were middle-age women, I could not identify other common features, such as the schooling level, the job or the socio-economical status. A problematic life story, characterized by losses and sad events was instead reported by all of them and was indicated as related to their condition.

*R. wanted to know about the questions that I had prepared for them, and I replied her that I preferred to talk all together about their stay at Riolo and their thoughts after the first week of treatments. "I haven't noticed any improvement", P. said; the other patients did not agree with her. P. had soon appeared to me very smart, and also very angry. The worst aspect of fibromyalgia, she said, was the fibro-fog, "that symptom which gives you confusion, as having fog in your mind; you cannot concentrate, not even speak or listen to the other people." This aspect, in P.'s view,*

*was scarcely taken in account by the physicians, while for her, it was one of the worst and most debilitating features of fibromyalgia. "I am scared to death to lose my intellectual faculties", she concluded.*

*Even if her pain had remained the same, D. had instead noticed improvements with the stiffness: "it is difficult to explain this pain, because we always say that we have pain, but the truth is that it comes and goes." Moreover, another fundamental issue in her view was the shift in one's own body perception: "I have become a person with another body. Before, I was not conscious of my body, I moved it wherever I wanted to, I never took much care of it... maybe because of my education." Things had changed, though, after the insurgence of fibromyalgia and she had realized that she was not capable to deal with the chronicity of her condition. D. saw a long-lasting treatment with cortisone as one of the causes of her condition. "I took it for years, but it was not beneficial for the pain and now, because of that, I also have the blood results all wrong, and my son has fibromyalgia too...", and she started crying. L. went to her and hugged her, telling her to keep on crying, if she felt so. "When you are with us, you can cry. I cry often.", said L., and the other patients agreed.*

*In L.'s opinion, the most relevant issue of FMS was the fact that it forced to get very well organized, to plan all the activities, rest included. And then added: "Our body is like a battery: you consume it constantly, and then it's over. You have instead to spare it." Another metaphor that she had found particularly adequate to describe her state was that of the "ten matchsticks": "you have ten matchsticks available every*

*day and you need to measure them out, because, if you finish them but the day is not over, then you are over.”*

*All the patients agreed on the fact that fibromyalgia had changed them, even if, for some of them, this was a positive thing, while not for others; E., for example, said that FMS had forced her to become a very choosy person, and this was positive: “not everyone understands; I’ve lost many friends because of that. All my expectations have been disappointed. Maybe you also have to reduce them, and to learn asking people for help, when you need it. Fibromyalgia has taught me so.”*

*I decided to take advantage of the situation which appeared fertile for a wider discussion, and I asked them if they could indicate a triggering cause (or more) of their fibromyalgia. L. replied immediately: “the cause of fibromyalgia is life; I started working when I was a child, then my ex-husband, the divorce...” E. did not agree: “It is not life, it is how you take life. What we share is that we are sensitive people, very altruistic; when you give everything away, than you remain with nothing.” L. continued: “Every evening I said to myself that I would have not gone anymore to work and, the day after, I came back. The same with my wedding: after the divorce, I had a terrible depression, I wanted to commit suicide, and I had pain-all-over... because when you collapse, you do collapse in your wholeness.”*

*Suddenly, E. said: “We all need a psychologist, because she helps you to stop when you have to.” And then, referring to me: “you too should think about it, for your work. It is important to know when to stop, because outdrawing everything may be devastating.” E. was clearly telling me that she believed that with my questions I had*

*going too far, and reprimanded also L. who had forced, in her opinion, D. to open up before. After a while, D. came back and, pressed by L, started speaking again. "I had many pains in my life: the sons went away, my husband never was a tender person", she said, and started crying again. What hurt her the most was that she had always been a very tidy person, while lastly she could not do anymore housekeeping: "then, when you are so tired, and you cannot do anything, sadness comes." She didn't have the feeling of controlling anything, her home as her life, and this made her visibly miserable. P. told her that she had to talk about this feelings with the doctors and that she should also had to evaluate taking antidepressants. "Sadness can dominate you, you have to do something about it; I take Prozac. It is a vicious circle: I'm in pain, I cannot do my activities and handle my personal relationships, I get depressed, and then again, I feel pain and so on..." D. commented that P. did not look like a fibromyalgic, and P. replied: "FMS is just something which inserts in a specific behaviour and life conditions."*

In my observation at S.Orsola, physicians-patients interactions had almost completely dealt with the ways in which fibromyalgia negatively affected the patients' lives. In the sufferers' reports, the relationship between FMS and life' issues emerged as much more intricate: in these accounts, the reasons and the pathological features of fibromyalgia appeared strongly bounded to the personal experiences and, therefore, hardly accountable for by a common framework. A noteworthy aspect arisen from the confront between the sufferers' views was that of the impact of fibromyalgia on their lives, as an event which had profoundly marked the course of

their stories, by leading them to change. Furthermore, although pain emerged as a predominant feature, other issues contributing to the sufferers' distress, above all in everyday life. In this regard, the ways in which each person had handled her condition, more than the severity of it, characterized the different conceptions of fibromyalgia.

#### *4.3.3 Visualizing pain: photography as a tool to unravel patients' experiences of illness*

The reflection on my topic of research, i.e. the ways in which fibromyalgia was defined by the patients and defined their experiences of illness, led me also to a further reflection on my methodology of investigation. Asking the patients questions on the aspects I aimed at investigate could have certainly allowed me to obtain some information, but I wanted to find a tool to get as close as possible to their experiences by putting in the foreground their own perspectives instead of mine, trying to diminish the bias related to my own view of the "fibromyalgia issue". At the end of the project, I gave to each patient a short list of questions focused on their pain and their illness' experiences. My questions were four: i) could you describe the place that pain has in your everyday life? If it helps, you may use some examples, ii) could you try to give a definition of "pain"? You can use examples, images, metaphors, quotations, iii) In your opinion, does it make sense to speak about mental and physical pain? Does it make sense in relation to your experience? iv) Which is, in your view, the worst aspect of your condition? Almost all the patients replied to me and I saw these written interviews only as a starting point for a much wider enquiry. Moreover, I had noticed

that in the patients' narratives of their experiences, especially of pain, metaphors and images were employed very often. These figurative representations, powerfully meaningful, were, in my view, hard to be elicited through a research tool such a question/reply interview. So I decided to employ photography as a method of research, interviewing patients by asking them to refer to photographs representing pain experiences.<sup>112</sup> The images I used were those collected in a book entitled *Perceptions of pain*, presenting the results of a work on chronic pain sufferers' experiences of pain; these pictures, produced by the patients of a Pain Unit (INPUT) at St Thomas' Hospital in London in collaboration with the English photographer and chronic pain sufferer Deborah Padfield, were the photographic representations of the sufferers' pain experiences. (Padfield, 2003)

Subsequently, I asked to my informants to produce their own visual narratives of living with fibromyalgic syndrome, by providing them with a disposable camera and a notebook in which I asked them to note a description of the photos taken. I interviewed five patients, four of which produced also the photo-narrative. In the following pages, I will present the findings of this research, which will be discussed in the conclusion of this section.

### *J.'s living with fibromyalgia*

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<sup>112</sup> For a synopsis of the literature on photography as a tool for social research, see: Banks, Morphy, 1999, and Harper, 1984. Harper is also the founder of the review *Visual Sociology*, collecting scholars' articles concerning the use of visual methods for the social research. A general up-to-date overview of the literature on visual methods for the social research is available at: [sru.soc.surrey.ac.uk/SRU40.html](http://sru.soc.surrey.ac.uk/SRU40.html)

J. is a 30 years old girl from Slovakia. When I met her, she lived in a little town not far from Riolo Terme with her mate and his family, composed by a sister and the elder parents. When J. was 20, she came to Italy to find a job, and she remained here because of her boyfriend. J. is a very smart and funny girl, even if clearly strongly distressed by her condition. Every time she moved, it was clear that she felt very rigid and sometimes she slightly limped because of a pain in her right knee. She has done a tailor school and makes some tailor works for private clients as well as stage costumes for acting companies; this is also her biggest passion, even if it is very hard for her to sustain with it.

I followed J.'s rheumatologic consultation the first day at Riolo; J. had already participated to the program the year before<sup>113</sup>, after which she had felt better for three months. Anyway, her current condition was very bad: her pain was almost constant and she often woke up during the night because of cramps in her legs. J. had been diagnosed with FMS two years before, even if she had terrible pains since she was about 8 years old; during the years, she had seen every sort of specialist, but no one had ever indicated a cause for her distress, before the FMS diagnosis.

I met J. the penultimate day of observation at Riolo. The other patients were doing therapy while she had to wait for her mate; I asked her to talk for a while about the project and her situation, and she agreed. While the previous year she had noticed some improvements in her condition after the treatment at Riolo, that year she felt as bad as usual. I explained her the reason of my interest in fibromyalgia and

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<sup>113</sup> What I followed in Riolo was the second year of *Progetto Benessere*

particularly in the patients' perspectives on the origin of the condition. She stated: "the cause of fibromyalgia is life." She started telling me about her medical history, lasting for 13 years of rheumatologic consultations, keeping on listening to the same conclusion: "There isn't anything, there isn't anything." J. saw her health problems as hereditary: her father had spent his life going to rheumatologists but he never found a solution to his pains. Also J.'s mother had always had severe back pains. "And this is why her nervous system collapsed, so she had to start taking chronically drugs. Sometimes, she had so much pain that she fainted." I wanted to know more about her thoughts on the reasons of her condition, so I tried to make my question more general: "Have you ever wondered which is the cause of your suffering?" J. was quite sure that the reason was life. "Life, life's traumas. The boys I had never treated me well. When I was little, I was always on my own, then my brother got sick and I remained all alone. I also felt very bad at school because I could not concentrate."

Suddenly, her mate, M., arrived. J. asked me if we could continue the talk with him, and I agreed, also because he did not seem willing to leave. J. went on telling her story, but using the plural "we". "We have been together for many years, and he is very patient with me... at the beginning, when I could not sleep at night, I kept on crying, and he stayed with me. He is very patient because he has a fibromyalgic sister and also his parents are very sick." M. seemed in a hurry so I asked J. the last question about the recognition of FMS, if this would have entailed any change in her situation. "Yes, indeed. Above all for the job. I cannot work now, I am too tired and I only have the energies to do casual works, but it is not enough. Besides, I have to



pay for all my medicines and M. has not a fixed job either, so we live hand to mouth. If fibromyalgia was recognized, maybe living could be easier for us.” M. leaved then for a couple of minutes and J. added that another major issue for her was that of having children. “With this disease, I am afraid to have children of my own because I could not take care of them...”

J. was one of the patients who replied to my letter and who agreed to participate to the photography project. As for the other patients, J. asked me to visit her at home. She picked me up at the railway station and we went home. I asked her how she was, and she started immediately talking about the job. One month before, she had found a tailor’s shop looking for a person to hire. Even if the boss was very impressed by the quality of her work, she needed a full-time worker. For J., a part-time job was already a lot, so she had to say no. This thing made her very miserable, also because even if seamstresses were quite wanted, she could not guarantee a constant availability, so she thought that finding a job would have been impossible for her. Also, she had lately contracted an ulcerous proctitis which forced her to stay at home, in addition to her leg, which had started hurting again.

I explained J. about my project and even if she liked the idea of the photographic interview a lot, that was very difficult because she was very distracted and clearly wanted to talk about something else. However, she went through the pages of the book and then pointed at the back of the book’s cover, and said: “This is it, this is how I feel: it’s all black.” I tried to draw her attention on the first photographs of the book, by asking if any image had particular meaning for her. “Wounds”, she said, by

indicating a photograph showing a leg pierced by swords. “It is like a battle, during the night. When I wake up, I always feel as someone has beaten me while I was sleeping.” This image recalled her also a TV program that she often watched, where surgeon pursued operations. “I watch it often, in order to see if this can impress me, but no, I do not feel anything. I also dream very often of wars, catastrophes...” It was clear that J. was very sad, so I asked her if she preferred to quit the interview and do something else, but she wanted to try again. I realized that that day she was very confused, she had many difficulties at following the conversation and sometimes she forgot about my questions and about what she was saying. She confirmed my impression and told me that while she was speaking, some images arose in her mind and made her lose the concentration. “It is always difficult for me to concentrate, I cannot communicate... I don’t know if it is the FMS.”

Another image which stroke her was that of the drugs. These were three black and white pictures showing some medications. “I have a box with my medicines”, and she showed me a very big carton box that she kept next to the bed with a huge quantity of drugs. Every day she took about five different medications plus some creams that she put on the painful parts of her body. “Paroxetine<sup>114</sup> keeps me calm and quiet. Because when the pain takes you and you feel so bad, you become a beast. The same was with my mum: she had very strong attacks, until she fainted and we had to take her to the First Aid.” In J.’s perspective, mental and physical pain were deeply tied: “for both of us, me and my mum, when the pain gets very strong, then it takes

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<sup>114</sup> Paroxetine is a SNRI

you also in the head. When everything's bad, you also get depressed.” Notwithstanding this, mental and physical pain were not the same thing. In the letter, J. made a distinction between them, by seeing mental pain as that arising when one is stressed and which may anticipate the physical one. But it may also go differently: “When the physical pain reaches the muscles, I am okay until I can bear it, but when I cannot make it anymore, the nervous state arrives.” While watching the other photos, she saw the image of a bath tub. She looked away and then, sighing, she said: “Having a relaxing bath, reading, sewing, all the things that I cannot do.” And then, looking at the picture of a hamster in a cage, she claimed: “It is like that, I feel entrapped, I cannot do anything.”

One of the main issues emerging from J.'s words was the impossibility to do the things that she loved, like sewing, but, more generally, it was an inability to do any kind of things because of the deep exhaustion, of the tiredness, of the lack of concentration, of her memory losses. J. would have liked to do many things, mainly the basic things that anyone does, such as working and having hobbies, but even if she sometimes tried to start an activity, then she had to leave it unfinished. This “uncanniness” was clearly related to the dark perception of her future, another frequent topic in her discourse. “I cannot see anything in the future”, she often claimed. All these issues emerged from the story that J. told then with her pictures. At first, my proposal, to do a photo-novella, did not convince her very much: she was afraid that she would not have been able to do it, she had no idea where to start from. We walked for a while and I asked her if she could see anything around us

which could represent how she felt. She indicated a shabby wall in front of us and said: “that’s it, that’s how I feel: ugly like that, in my head.”



*The color has been taken away from the wall and I feel as if the pain is taking away my soul. It is sad*



*I do not feel my hands anymore, I only feel a heavy and iced stone pushing down my hand*



*I hate having to make my bed. It is such a strain!! After 30 minutes I cannot do it anymore, maybe I can call the Parliament, so they come and help me!?*





*I sewed my finger, I have lost the clarity of thoughts, everything's dark, I had lost my mind. Darkness: how can you sleep in this state? How many punches I got without knowing...*



*I do not want to go to bed, my back hurts. Another night tossing and turning.*

*My muscles are burning, I cannot stay in the bed, who can sleep in this condition?*

*It's 2 am and I look at the ceiling. I live as a bat and during the day I am a mummy*



*Yesterday I lost my knees, a terrible pain, I could not reach the bathroom*

*How many other times will I have to put the ointment on the knees for the pain?*

*Then, after 5 minutes their effect is over. Injections, without them, I cannot survive*

A couple of months later, I met J. again, while I was going to meet another informant. J. was very glad: she had spent the summer in Prague, where her brother lived. There, she had met a Filipino healer who had treated her: she had no more pain and she had stopped taking every medication. According to her, the healer had “assembled all the pains in her stomach and, through the laying on of the hands” he had thrown away all the suffering from her body. Soon this healer would have come to Italy and she was planning to go seeing him again. J. had also a new project: she

was planning to open a tailor's corner in the dress shop of a friend of her and she was thrilled by that. Six months later, I spoke again with J.; her pains had come back, and she had started the acupuncture treatment in a local clinic. She had not have improvements yet.

Even though J.'s "miraculous healing" seems to justify an interpretation of her pain as a purely psychological problem, such an account appears unfulfilling when applied to J.'s whole situation. By referring to her narrative, it is clear that, beside the constant and severe pain, the causes of her suffering go well beyond this aspect and concern life' issues and the difficulty of dealing with them. In this sense, what would entail on a pragmatic standpoint framing J.'s condition as a psychological problem? Probably, the pharmacological management would not significantly change since J. is already treated with antidepressants. Of course, J. should not refer anymore to a rheumatologist but to a psychiatrist. Her wandering from one doctor to another would simply continues and, instead of having a fibromyalgia diagnosis, she would probably have a depression one. I believe that the most important question to be tackled is: would this hypothetic re-classification of her condition contribute to improve J.'s situation, would this reallocation of her distress entail an alleviation of her suffering?

#### *R.'s living with fibromyalgia*

R. is a 40 years old woman, she lives close to Bologna with her two daughters and the husband. When I met her, she was working in a hospital as a employee, but she had worked for many years as healthcare worker. I got to know her better during the program at Riolo and we remained in contact for the letter-interview and the



photography project. I went to meet her at her home one week after I saw J., and we spent the whole day together. Our photographic interview was quite long, it lasted for about one hour and a half since R. was very involved in the work and she commented on every image she saw.

While leafing through the book's pages, R. got immediately stuck by the picture of a man's face, and said: "yes, I get it: his face, his face is changing. Sometimes people look at my face and tell me: You're not okay, are you? My face changes, maybe it's also because of my attitude, of closure..." What other people thought when looking at her was a frequent reflection that the book's pictures recalled to R. This issue was strongly related to what R., as many other patients I spoke with, saw as one of the most troublesome issues of fibromyalgia, i.e. the cognitive problems. R. reported to be often in a state of confusion in which "you are not able anymore to do 2 plus 2", a metaphoric expression meaning that one is not able to do even the most simple things, like an easy calculation; these "episodes" gave R. a lot of discomfort when she was with other people. In the scientific language, this cognitive dysfunction is labeled as fibro-fog. In the patients narratives, this term coincided with: i) a general state of confusion, ii) dizziness, iii) difficulty at concentrating, iv) problems at following other people or one's own discourses, v) memory losses vi) a feeling of disorientation causing troubles at moving and walking and, finally, vi) general problems at expressing one's own thoughts. It was clear that while we were speaking, she was sometimes having these episodes and, like J., was worried that I could not understand her because she could not explain herself properly. R. told me that a

couple of weeks before she wanted to come to Bologna, but, when she reached the railway station, she started feeling dizzy so she changed her mind and went back home. This decision was motivated by the fact that she was afraid not to be able to speak with people when arrived in Bologna. These cognitive problems, which in the patients' perspective were scarcely taken in account by clinicians, represented one of the most painful aspects of FMS.



*When you are limited in the everyday life, you have to think about some tricks to do the most simple things: like using the washing machine without arching over. And while watching the clothes in the machine, I think that my thoughts resemble these clothes: they intertwine, they are confused and you don't have one clear thought anymore. The only thing you can do then is go to sleep and make your head rest*

In R.'s view, these issues represented the evil character of fibromyalgia, because they were strongly debilitating but invisible to the other people. We discussed a lot about a photograph framing the scars on the arm of a patient who self-inflicted in order to show to the people surrounding her suffering, who otherwise, in this patient's opinion, could not have understood her. R. agreed with this patient's complain "because mental confusion... is not... I don't know how to say... it's not something that you see, it just comes out sometimes and you cannot do 2 plus 2." This was also the reason why she "envied" visibly-disabled people: "those people on the wheelchair or with an amputated limb, who anyway do sports, who are full of energies... while I cannot do anything because my (condition) is global."



*"Look at that boy on the wheelchair: poor him! Look at that old man all alone in a hospital bed, who knows how many things he did in his life, and look at him now..."*

*How many times I heard these words. But with pain, it is different; maybe it is not so strong, you don't need to take analgesics, or it is chronic, the pain you get used to, slowly increasing, so you think "I cannot take anything now: what if it gets worse?" This is the pain you cannot explain to the other people, because they cannot see it; you too have to forget about it because, otherwise, people won't understand you. So, your physical pain turns into mental pain, a pain inside. Why is it so difficult to understand? I have to be the wrong one.*

*When I met other people with FMS, I felt understood while speaking with them, sharing our experiences. So, I thought, the strange person is not me! It is people around me who do not get it, it is the misinformation, the ignorance, the fact that this disease is poorly understood*

In addition to the pictures that she took, R. found also other images on the web evocative of her situation: among these, she picked a photo of a man sat in the dark alone; "loneliness" was the title she gave to this image, and commented on it by saying that her pain often caused solitude. She often preferred to stay on her own instead of having to justify her behaviors with the other people: "justify myself because I am tired and I don't want to go out, because I feel sad, because I have so much pain that any movement could make me to groan. So, I say: don't worry for me, I stay at home, you go, while I know that I would like so much to go out, to walk, to see things." Even if R. never spoke explicitly about the medications' issue, this topic emerged many times in our conversation. Unlike the other patients, R. was not

following a specific therapy for FMS, she just took analgesics when the pain was unbearable. At the same time, R. did not want to take any drug, so she often waited until she could bear no more the pain to take the painkillers. “Once, I was feeling so much pain that I took three painkillers: I scared myself that time.” It often happened that she avoided doing things because of the fear that, after, she would have been obliged to use something for the pain. She defined the medications as “truly temptations”, from which one had to keep far from because “if you start taking an analgesic every time you feel pain, you will spend your whole life taking them.”

R. often expressed her feeling as that of being entrapped, by referring to a picture representing a person which seemed thwarted to escape from a red net wrapping her up. The mental entrapment experienced by R. was coupled by a physical one, represented by the metaphor of the glue, or the chewing-gum, as something she was sinking into and limiting any movement of her. “Sometimes I feel as if my own body produced glue.” This metaphor proved to be particularly useful to R. in order to describe her experience: the glue did not solely limit her movements, but also any kind of operation, physical and mental. Moreover, the extent of this situation was so overwhelming that R. felt as if her body itself was generating glue.

R. had spent long periods characterized by strong functional limitations because of the pain. She had problems at walking, and sometimes she had to stop, because she felt that she could not go on; “the worst thing was seeing 80- years old nannies passing you in the street; so you pretend that you are watching the shop windows or that you are calling someone. You cannot just stop and stay there, in the middle of

the sidewalk...” Another image that recalled her how she felt in those moments was a memory of when she was a girl and went to the gym. “After the first exercises, you feel the lactic acid in your legs and the instructor says: move, move! But you cannot, I cannot move.”



*How can I make it now? Some days I can do the stairs, but some other days you have to do the steps one by one and you are not allowed to be scared of the elevator*

The job was another pivotal issue in R.’s narrative. When we met for the interview, she was working 30 hours a week, 6 hours per day. Even if she already had had a reduction in her timetable, still, at the sixth hour she felt “devasted” and she did not even have the energy to go to the canteen, so she rested for a while and then went home. She had asked to change her timetable in order to go to work only in the morning, when she felt more active and also because she had problems driving at

night. Nevertheless, she could not present any disability certificate motivating her request, so she waited and tried to manage the situation anyway. The job issue was relevant in her story also for another reason: R. saw in fact the triggering cause of her fibromyalgia an episode happened when she was working as healthcare worker at the hospital. Once, while she was picking a patient up to move him to another bed, she felt a terrible pain and she discovered then an hernia in her back. However, R. believed that fibromyalgia's causation was not that specific event, which could have just worsened a pre-existing situation; the "true cause is for sure a genetic predisposition", she claimed.

R. was constantly fatigued and this forced her to sleep for a couple of hours every time she finished to work, so she had few time to do housekeeping works. R. had therefore to plan very well every day, by including short rests after every activity. Then, "you have so many ideas, you want to do so many things, so many expectations... but you cannot. So you are pleased anyway by doing fewer things, by doing them slower."





*My pain thwarts me from doing the things I love more, as taking care of my garden. The weeds get the better of my little flowers which slowly disappear...*

This situation is well represented in R.'s view by the image of a falling castle of cards: "living this way means also renouncing at doing things perfectly."





*My pain makes me do everything slower, physically speaking. But also mentally, because thinking about the things to do is more difficult. There are so many things to do, my head is crowded. So, I take a break and I ask myself: What is it more important to do now? Today I do this, tomorrow we'll see if I will be able to do what's left. I often, very often, have to rest!*

Going through the pages of *Perceptions of pain*, R. indicated many pictures which could well represent her fibromyalgia-pains: i) red-hot iron was the severe pain, like that caused by medieval tortures, ii) migraine pain was that changing the person's look, as if a part of your face was thrown away, iii) the image of a fork in the flesh recalled those piercing pains which come all together, iv) the jubilee clip was the

biting pain, as if an animal was biting and tearing her body to pieces. Pain was also something she wanted to escape from, like a prison, or a cage. But she could not, because of the glue.

The photo R. liked the most was that of the apple. Even if that photo actually represented a rotten apple, R. claimed that she saw the apple as only bruised. “It is like a body full of livid, it has not been treated well. It’s like the apple, you have to be gentle with it, you have to place it in the bag smoothly; if you throw the apple away, it gets bruised and nobody wants it anymore. I feel like that, but not bad as a rotten apple, I am not like that other picture of rubbish!” If one’s own body was something to care about, this often represented also a prison. Among the images that R. had found to communicate me what living with fibromyalgia was like, there was also a detail of Michelangelo’s statue *Le prigioni* (The prisons). R. commented: “sometimes your body is a prison. You would like to do many things, but you have to remain quiet and still instead. And my body is silent and groaning in the rock, waiting for someone to understand that and help me come out from this rock block imprisoning me.”

#### *L.’s living with fibromyalgia*

L. is a middle-age woman diagnosed with FMS twenty years before. As J., she had already participated to the first edition of *Progetto Benessere* and she evaluated positively the experience.

In the years, L. had tried different therapies, among which a trial study on the employment of Milnacipran<sup>115</sup> for the treatment of fibromyalgia. This drug had ameliorated her symptomatology, even if, after one year, the trial had ended, and so had the therapy. At that time, the patient was taking Pregabalin and Venlafaxine, which were only partially beneficial to her.

A couple of months before going to Riolo Terme, L. had had an experience that had scared her a lot and she wanted to tell me about it. She had decided to go to UK to visit her daughter, who was living there. The flight went well but, as soon as she arrived in the hotel, she started feeling very bad, so she went to the bathroom sweating and feeling very dizzy; the next thing she remembered was her daughter asking her if she was alright. The patient had been unconscious for more than five hours, so she went with the daughter to the hospital where several analyses were run, all negative. When she had asked a professional opinion to the rheumatologist in Riolo, the physician had told her that probably had had a TIA (transient ischemic attack), that was something that could happen. However, this explanation had not satisfied her, who kept on asking: “how is it possible that I lost almost one day of my life that way?”

I met L. for the interview some time after R., at her home. As soon as had we started talking, she told me about her last travel in the UK; She went there with a

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<sup>115</sup> Milnacipran is a SNRI used in the treatment of depression as well as for FMS. In 2009, the FDA has approved this drug in the US for the management of fibromyalgia and even though this medicine was first launched on the market in France (1996) for the treatment of major depressive episodes, today it is widely recommended in the treatment of FMS, but not for depression

friend of her and her daughter. Before leaving, she was very scared of the possibility to “have an attack” during the trip. In the end, everything went well, even if she had an attack of acute pain and vertigos so for almost one hour she was not able to speak and listen to anyone.



*When you have to go on holiday, having to drive is a torture: you want to leave, and you know that taking a rest is good for you, but it is all so stressful: driving, unpacking, and so on, while you only want to sleep. If they propose you an organized trip you say no, you find one million excuses because you feel embarrassed, you don't want to condition the other people...*



*The rutty ground. It happens sometimes that while I am walking, I stumble, as if it was a huge step; but there is nothing, it is my instability. It is as if the legs all of a sudden got blocked and I risked to fall*

L. liked a lot the idea of conducting an interview with the images on pain perceptions, even if most of the pictures she saw were not evocative of her own pains. This tool was helpful anyway, because for every photo she did not find meaningful, she tried to tell me why and how she felt instead. Hot objects' images were reminiscent because her pain was mainly burning, as a red-hot iron wire; another image she found interesting was that of a bone overlapping with a barbed wire: "my pain resembles a barbed wire that pierces your body, and it is also hot, like fire the you feel inside when you are in bed. It is also something that curbs you, and it is very hard to get rid of it. Sometimes it is so strong that I just feel like crying. I have



not a true depression, but a general sadness brought about by the awareness that my condition won't change; those times I ask to myself: what is the sense of it, of living like that? But then I realize that there is no point at complaining, and I try to go out, to do something else."



*Sometimes it is as if I was walking in a field of nettles and underbrush, piercing, skinning and burning you. It is like an invisible hand whacking your body and you don't know how to calm it down*

L.'s images of pain were often related to the sensation of being pierced, in several ways; she felt as if there were swords piercing her back, coming from the hips and the shoulders and crossing in the centre of her back. Another frequent metaphor that L. used to describe her pain was that of a bite: "pain is something that bites you in

the flesh, tearing your body apart and attacking you here, there, and covering your whole body, violently eating it". L. told me that sometimes she found hard to understand if this feeling, of being bitten by a furious dog, was a nightmare or something that she actually had felt. "During the day, you try to cover up your pain, to hide it to the other people and to yourself, but in the night you cannot. Sometimes, you woke up so rigid and painful and you would like to do something, but you cannot..." This was the darkness L. often talked about, and which she recognized in many photos having a dark background, like in those days when she was very bad, when "you cannot even see a small opening... like last Sunday, I only felt a bit better lying in the bed, also reaching the bathroom was stressful for me."

In L.'s narration, as in J. and R.' ones, most of the metaphors of pain were characterized by expressions referring to potential causes of physical damage.<sup>116</sup> In these cases, the descriptions were particularly vivid and precise, with a specific reference to the body parts involved. The bad feelings, instead, such as L.'s "darkness", appeared more blurred and hardly relatable to bodily localization; moreover, the cause was not a reference employed in the description, and examples of concrete situations were preferred instead.

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<sup>116</sup> Semino, 2010 argues that, in the descriptions of pain experiences, expressions referring to potential causes of tissue damage are often employed. When the experience conveyed is not clearly related to such a damage, these expressions are used metaphorically. This, Semino maintains, is due to the fact that these expressions may facilitate embodied simulation of the painful experiences and, therefore, stimulate an empathic response in the listener



*Today I had guests for lunch so I have cooked. When I had to tidy up, I was so painful and stiff... I couldn't. I cannot even grab the sponge, I am sure that the dishes would fall from my hands*

During these days, as in a photograph showing an iced hand, she felt “entrapped in a glacier from where you cannot escape, you are stuck in the ice.” Sensations of cold and ice often occurred in L.’s descriptions, also because she usually had half of the body iced and the other half burning: “my feet and my legs are always in a fire, while the arms are freezing. You would go mad if you slept with me, because I need to have the lower part of the body completely uncovered and the upper one wholly covered.”





*This is the cold that I feel in the upper part of my body, as if I am immersed in a waterfall of cold water and the arms are iced, it's impossible to warm them up*



*(...) and the feet are burning like fire*

In L.'s narrative, the burning pain in the legs and in the feet came after demanding days, when she had consumed too much energy. "Time and energies are for fibromyalgic sufferers something to which one has to pay attention to." As in the accounts of other patients, L. saw the lack of energies as one of the worst aspects of FMS: "you always feel like an unloaded battery; so, you have to spare your energies during the day because when you have consumed all of them, you are off, you cannot do anything else."

Her pain emerged often as a restriction, represented by the metaphor of an elastic coverall: "at a certain point, you can hear the bell ringing that means that your pain is telling you to stop, the pain will not let you go anywhere..."; as in the picture of a tied whistle, pain was a boundary, separating what she wanted from what she actually could do.



*Today I worked more than usual and I feel as I had a rock on the top of my body pushing me. I cannot move because the pain is so strong that it takes me away any will*

The condition of people living with fibromyalgia could be framed, in L.'s view, by the photo of the rubbish. "Rubbish is meaningful in our experiences under several respects: sometimes the pain makes you actually feel as you, especially your body, were rubbish, to be thrown away. I think that many FMS sufferers may also feel as rubbish because their suffering is dismissed, and their disease is not recognized by the clinicians; I have been lucky in this sense, since my doctors have never doubted of the truth of my pain, but I spoke with many people who, instead, were not so lucky..." Moreover, having fibromyalgia meant to L. being dependent on the medicines, on many of them. These drugs helped to take under control the physical pain, to calm it; "the seeds of mental pain, instead, you cannot do anything with that. You can overcome it only with a huge willpower." Pharmacological treatment had, in L.'s life, an ambiguous place: "we are laboratory animals, we are. And for me, it is a pleasure being a test animal, if this can help other people." When L. participated to the trial with Milnacipran, she was very happy to do so. Beside the fact that it was beneficial for her symptoms, she felt that she was somehow contributing to scientific research on fibromyalgia, which in the future could help other people. "People told me that I was crazy, and I told them: who cares? Even if I'll die tomorrow, it would be worth, compared to the possibility of not having pain anymore. See, I don't know

what it means living without pain...the first time my back started hurting me, I was 12, and my memories don't go farther..."

*E.'s living with fibromyalgia*

E. is a middle-age woman from city quite close to Bologna. As J. and R., E. had already participated to the first edition of *Progetto Benessere*. I met her the year before during a conference on fibromyalgia held in Riolo Terme. At that time, we had spoken for a while, and she had told me that she was trying to make an appointment with a Swiss physician whose therapy for fibromyalgia had had positive outcomes. When I met her again in Riolo, I learnt that she had started practicing Buddhism and, even if she was following a pharmacological therapy, she judged her condition's improvement as directly due to the beneficial effects of the Buddhist practices. The influence of this experience on her conception of FMS was already evident in her letter: "One has to deal with fibromyalgia by taking in account body and mind, which are inseparable: the search for the best treatment is wholly individual and entails finding the appropriate therapies by considering both: everything provides body relaxation, brightens up also the mind which, in turn, is beneficial to the body."

E.'s experience, as it emerged through the photographic interview, was that of a profound change, which had entailed a noteworthy shift in her conception of how to deal with FMS as well as in her wellbeing. "When you live with chronic pain, you are forced to reorganize your life and constantly change your priorities"; living with fibromyalgic syndrome meant accepting it, and learning from it "how to behave, how to weigh one's own energies and also how to react to the worst pain crises."

The pain, that E. often defined as waving, remained, but her approach to it had deeply changed: “I pay a lot of attention to myself, so now I can recognize when and *why*<sup>117</sup> the pain arises. For me it is often related to tiredness, or consequent to anger.” The comprehension of the relationship between her life experiences and pain had helped her change the attitude towards the worst crisis. “I remember a very terrible day, years ago, when I almost collapsed under a tree. I had fought with a person who had made me very angry, and I went crazy. I felt deeply confused and overwhelmed by the pain, and I realized that I could not allow myself to feel so bad again.”

An image that E. recognized as familiar among the book’s photos was that of the armor. “Sometimes it is as if my body was imprisoned in an armor, something that bridles you, and you are there inside, completely covered by it. You can use your eyes, but the rest of is completely blocked... that time, when I had that terrible attack, I felt that there was no space at all between my body and the armor.”

However, things had changed, and this was much related to the way she dealt with her life in general, especially with her personal relationships. “Once, I always put into play all myself and when things went wrong, I had a terrible pains. I have always been a very sensitive and willing person, as most of us (fibromyalgic sufferers), and then, we usually got screwed... now I keep on helping other people, but I know that in order to do that, I have to feel fine first.” By limiting her possibilities, fibromyalgia had helped her to re-evaluate her personal relations, i.e. which relations were worth

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<sup>117</sup> My emphasis

to maintain and which weren't. "Sometimes you plan to do something with someone, but then you are stroked by a pain attack and you have to stay in bed, on your own. Someone gets it, other people don't."

E. often referred to the Buddhist recitation as a powerful tool which she resorted to when her condition got worse. "Recitation means taking your life back and turning the dark side into something to learn from, by understanding where it comes from." One year before, she had an "enlightenment" when she had realized that all her problems were related to her fear to be abandoned, traceable back to a "traumatic" experience in her childhood: "my parents were hotel managers and sometimes they forgot about me and left me alone in bed for one day. I am currently working on this, but I am already ahead, because, at least, I have found the cause." In E.'s narrative, as in other patients' stories, there was a strong connection between life issues and the symptomatic manifestations of FMS, such as pain. Nevertheless, in E.'s case, such a relationship was not a straightforward cause and effect one, but it appeared more a co-occurrence of emotional and physical pains. At the same time, the shift in the approach to her suffering had been global, and she often compared the way she was currently dealing with her personal issues to the way she was managing her FMS' symptoms. "Now, when I have a pain crisis, I lie in bed and wait for it to fade. I can do it also because I am now living my life peacefully, I am not depressed, even if I have been in the past and I know what it means to react with sadness to pain, to the life events."

Notwithstanding the positive results brought about by her renewed approach to fibromyalgia, E. kept on having severe pain attacks, described, by referring to the images of *Perceptions of pain*, as burning like a hot spear, when the pain was particularly intense. Moreover, she sometimes felt as if sharp objects were, all of a sudden, piercing her body, especially in the lower parts and during the night. “Unlike my pain waves, I have never understood which is the cause of these stabs. I could identify a link between symptoms such as fatigue and physical stress to those occasions when I got very angry, but not with the stabs. For us, it is very important to pay attention to the wind and the season changes, we have to know how these things may affect our condition because in that way we can recognize when the wave will come and also that it will pass; if you get angry, it is worse: you just have to wait.”



*The boundary: I am not allowed to leave my body*





*A shadow appears and you try slowly to go out*



*Wrapped up in a net*



*Beyond the net: the wave is assuaging*





*Curbed again in the fronds*



*Beyond the frond: a cloud, the blue sky*



*Overwhelmed by another wave of intense  
intense pain*



*Pain blocks me; the keys to get out,  
the path is waiting for me*

#### *4.3.4 Defining and being defined by fibromyalgia: patients' experiences and the status of FMS as a disease*

In the conclusion of the previous section, I have emphasized the relevance of the patients' experiences of living with fibromyalgia in relation to my topic of research., i.e. the definition of FMS as a pathological entity. In this sense, the questions to be tackled are: what do the patients' experiences of illness tell us about fibromyalgia as a morbid condition? How do these experiences participate to the definition of the biomedical entity labeled "fibromyalgic syndrome"?

The causation issue is a topic to which I have paid a great deal of attention through my work, particularly because I believed that this matter could mark a relevant divide between physicians and patients' perspectives on fibromyalgia. My enquiry has brought me to conclude that in the clinicians' view, FMS' causation is usually not explicitly questioned in the practice; nevertheless, it is remarkable that beside the acknowledgment of the complexity of the causal frame of this condition, a psychological/psychiatric interpretation of fibromyalgic symptoms remains widely shared among clinicians; for the majority of the patients, even if FMS is never interpreted as a psychogenic condition, it is not even seen as caused by a precise organic cause, but, as reported by several patients, the origin of their symptomatology is retraceable in life's issues. At the same time, even if fibromyalgia is never defined as an organic pathology, still some patients are not completely sure that, particularly for pain, an organic problem will not be detected at a certain point. The patients usually do not indicate a specific event as the unique cause of their

condition, but present a more complex view which, according to the scientific conception of FMS, sees several predisposing factors as dormant until a traumatic event brings them to light by leading to the insurgence of fibromyalgic syndrome. The traumatic event, as indicated in scientific literature, may be an organic problem, such as an infection or a physical damage as a psychological one, such as a divorce or a series of unlucky life's events. In the patients' accounts, the psychological issues of fibromyalgia do not concur with a precise mental disorder, e.g., depression, but appear more as several and long-lasting life's issues; the life of the fibromyalgic patient is usually a painful one, characterized by sad and distressing events, or by traumatic events approached by the patients by feeling overpowered. In some cases, then, the insurgence of fibromyalgic syndrome represents the litmus paper of this situation, by leading them to a reflection on one's own life.

The issue of the distinction between mental and physical pain has been also investigated, both through the letters which questioned this topic specifically, as well as through the photos of pain which could well recall psychological as physical features of chronic pain's experience. For the majority of the patients, mental and physical pain do not coincide: physical pain is that perceived as something hurting in the body or the body as whole, while the mental one concurs with the emotional side of the pain experiences, i.e. the distress, the difficulty at bearing constant pain, the sadness and the despair. In this sense, mental pain is usually conceived of as a consequence of the physical one, the result of the impossibility to go on because of the limitations brought about by living with chronic pain. Moreover, in the patients'

perspective, the possibility to treat chronic pain would also mean the solution also to the emotional suffering. The gap between psychological and organic issues constituting fibromyalgic syndrome appears, in the patients' narratives, quite blurred: as for the causation issue and the relationship between mental and physical pains, almost all the patients see their fibromyalgia as a condition in between mind and body, i.e. characterized and characterizing both issues ascribed to the domain of the psyche as well as that of the soma. The presence of constant physical pain is, for almost all the fibromyalgic sufferers interviewed, directly connected and sustaining in a mutual way the emotional suffering and the problematic life's issues.

The employment of antidepressants does not even mark an inclination for a psychological interpretation of fibromyalgia; the effectiveness of these drugs, particularly SNRI as duloxetine and fluoxetine widely varies from patient to patient, but, generally, if some benefits occurred at the beginning of the treatment, they do not last longer, and the patients usually try to find alternative pharmacological therapies. Furthermore, if the biomedical, and particularly, pharmacological management of FMS is for the majority of the patients a positive thing, still this does not represent an ultimate cure for their condition, pushing most of the sufferers to look autonomously for other supports or to participate to clinical trials to test the efficacy of new medicines, hoping that a definitive cure for FMS is there to come. In the experiences of the patients I have spoken to, psychological therapies were instead not an option, although some patients have undertaken individual paths to reflect on personal issues which could concur at worsening their condition. Most of

them had searched for alternative ways to deal with their suffering, e.g., E., but no one had taken in account the possibility to see a psychologist, mostly because they saw of psychological issues affecting their lives as directly due to the presence of pain and the other distressing symptoms of fibromyalgia.

The gender issue, i.e. the noteworthy prevalence of women affected by fibromyalgia, never came out explicitly, also because I never addressed this issue when speaking with the patients. Nevertheless, in the patients' representations of the "fibromyalgic-type", these individuals are often depicted as very sensitive and vulnerable persons who had spent their lives taking care of others, disregarding themselves, features which can be coupled with the stereotype frequently encountered in the physicians' private talks of the fibromyalgic patient as a middle-age woman, often unemployed and mainly devoted to her family and to the housekeeping duties. In my experience, I have not ascertained the prevalence of fibromyalgic women coincident with this stereotype; what I have noticed, though, is a generally shared conception of the women as more prone to developing the issues characterizing this condition, such as depression, a lower pain threshold and, generally, a more acute "sensitivity", in virtue of genetic or cultural aspects more proper to women than to men<sup>118</sup>. In the patients' accounts, as well as in the perspectives of some physicians, having an heightened sensitivity, meaning both an

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<sup>118</sup> Even if in my dissertation I have not specifically addressed the gender issue, this topic appears to be particularly interesting and intriguing to be analyzed, particularly when looking at the percentages of women affected by the so-called functional somatic syndromes, many of these included in the CSS spectrum. The works of sociologist Barker on fibromyalgia have indeed focused also on this aspect of the question

emotional capacity as a physiological issue leading e.g., to perceive more the pain, was seen as typical of the feminine gender.

For what it concerns the definition of fibromyalgia as a disease, all the patients I have interviewed see FMS as a morbid entity in its own right. For most of them, the diagnosis of fibromyalgia has meant the end of a long-lasting, frustrating and painful search for a biomedical acknowledgment of their symptomatology. In addition, receiving a fibromyalgia diagnosis has also meant for many patients, the formal dismissal of a purely psychogenic interpretation of their symptoms; nonetheless, as it has been showed, fibromyalgic syndrome is still considered by many physicians mainly a psychological issue and many patients still feel that their suffering is dismissed by the physicians treating them.

As previously argued, the unresolved “fibromyalgia issue” affects, in different ways, both rheumatologists as well as FMS’ sufferers; the core question is the failure of the biomedical model in dealing with the suffering of people which have been diagnosed as having a medical condition characterized by a prominent symptom, the pain, which because of its location, becomes a rheumatologists’ competence; nevertheless, the clinical presentation of FMS is characterized by a much wider constellation of issues, e.g., the fibro-fog and the fatigue, which rheumatologists don’t know how to deal with. As suggested by some scholars working on fibromyalgia, as well as recognized by many physicians, the impasse presented by fibromyalgia is retraceable in the lack of an integrated approach to the complexity that characterizes conditions such as fibromyalgia. The endorsement of such a model, at least for what

it concerns of Italy, is far to come, even if some attempts in this regard are slowly appearing in the Antalgic Therapy Units in the wealthier regions, e.g., Emilia Romagna. Integrated approaches to chronic pain, such as that proposed by John J. Bonica for his pain clinic, remain instead in Italy at a private level, available therefore for a minority of the population. Moreover, the issue of the recognition of FMS as a disease presents many facets. When speaking about the recognition of their condition as a disease, I have been persuaded that the patients referred to different things: i) recognizing FMS as a “real” disease, i.e. not as a psychogenic problem, ii) recognizing that the severity of symptoms such as the pain or the fatigue are not due to a “mountain out of a molehill” attitude of the person, but to the presence of a pathological process, iii) recognizing fibromyalgia as a debilitating condition, leading therefore to some exemptions, e.g. for the drugs or facilitations for example to ask for different job conditions. With regard to the last issue, in our Country the exemption to the drugs’ expenses seems today hardly obtainable, because antidepressants belong to the class C of the medicines, i.e. they are entirely at the expense of the patient. At the same time, the recognition of the disability brought about by living with fibromyalgia, clearly witnessed by the patients’ narratives, remains a valuable option for these patients, which would have to ask also for a psychiatric visit to assess their distress.

Worthy to stress, from the patients’ interviews it appears that most of them are not against a psychological framing of their condition *per se*, but only when this conceptualization ends up coinciding with a therapeutic abandonment. Whatever the

collocation of FMS in the biomedical framework, this should be, first of all, a valid therapeutic option, providing solutions at least to control symptoms such as pain and dealing with other prominent issues such as the cognitive disturbances and the fatigue. Furthermore, the most urgent issue of FMS' patients is that of the consequences on everyday way of living with a debilitating condition such as fibromyalgic syndrome.

The question is if it acceptable to be so demanding with biomedicine, especially in the current scenario which appears instead to be going in the opposite direction, that of a restriction of the "cure" to a provision of services. As a matter of fact, it seems indubitable that the trend is today that of a reinforcement of the hyperspecialization and of an inclination to optimize (which often means reducing) the services provided to patients, always more considered as products-consumers instead of sufferers to be healed.

Nevertheless, fibromyalgia, as many other elusive conditions characterized by a deep suffering unaccounted for by the same biomedical framework which has named them, exists as a disease. Consequently, if suffering is today medicalized, then it is here that solutions are searched for by the sufferers. The conclusions that I have drawn from the patients' accounts of their experiences is that, even if only partially satisfied by the replies given from the biomedical system, fibromyalgia remains still reconfirmed by the patients as a biomedical condition, which therefore needs to be accounted for by moving from the biomedical framework in which it has arisen.



## Conclusion

Pain has always had a crucial place in medicine, especially because of its intimate relationship with disease. In the second half of the XX<sup>th</sup> century, a novel conception of pain starts arising in the scientific world and especially in biomedicine: pain is a troublesome object which deserves a specific attention. In addition to this, the possibility to alleviate some kind of pains, turns into one of the most urgent goals of medicine; the management of chronic pain represents today one of the most relevant issues in Western healthcare systems.

In my dissertation, I have conducted an investigation of this shift of paradigm in the relationship between biomedicine and pain. First of all, the renewed neurophysiological theorization of pain mechanisms has been presented; the definition of pain by the IASP has been analyzed in relation to the acknowledgment of the renewed perspective on the phenomenon and, finally, the different conceptualizations of pathological pains, i.e. psychogenic pain and chronic pain, have been discussed. The last chapter of the thesis completes the theoretical investigation with special reference to the definition of chronic pain as a disease with the findings of an ethnographic enquiry on fibromyalgic syndrome.

My work has particularly focused on biomedical attempts to recognize pain as a multidimensional entity, and especially as a pathological condition, deserving therefore a specific attention as a disease in its own right. Two intertwined aspects of this issue have been considered indicative of pain' re-conceptualization and have therefore been discussed throughout my work: the relationship between pain and

tissue damage, and the role played by psychological factors in pain. The denial of the coincidence between pain and a detectable injury in the body has its counterpart in the emphasis on psychological factors' influence on pain; moreover, these features represent a strong challenge to a science aiming at measuring, explaining, and, as for biomedicine, at treating its object of application. The localization issue, i.e. the definition of pain as correspondent to specific detectable structures, is emblematic of the resistance of the scientific approach to a new conception of pain as a deeply subjective and complex phenomenon, characterized by several intertwined features, physiological as well as psychological ones. Even though current neurophysiological theories acknowledge that pain is not the result of the stimulation of precise anatomical areas, still the "temptation of specificity" re-emerges in the ongoing attempt to identify the neural structures underlying pain experience.

In biomedicine, the question of pain' localization has another significance, which is directly related to the troublesome acknowledgment of pain as a pathological phenomenon in its own right. As witnessed by IASP's claim defining pain as an experience associated to an actual or potential tissue damage or tissue damage-like, pain keeps on being interpreted with respect to the presence (or the absence) of a detectable tissue damage. The persistence of this view appears in the conceptualizations of pathological pains. As is showed by the classifications of psychogenic pain, the absence of a detectable organic cause accounting for the presence of pain leads unavoidably to the conclusion that pain has to be caused by psychopathological problems, i.e. pain is a mental disorder.

Furthermore, the constitution of chronic pain as a disease is strongly bounded to the several interpretations given to the absence of a detectable organic damage accounting for the persistence of pain and of the role played by psychological factors. This has also led to the formulation of different conceptualizations of chronic pain as a disease, suggesting that there is not an univocal definition of the phenomenon, but many. The ways in which several conceptions of chronic pain as a disease interact is discussed in the last chapter of the dissertation in relation to fibromyalgic syndrome.

Today, although a multi-causal physiological and psychological framework accounting for chronic pain has been in theory advanced, in the clinical practice such an integrated management of these conditions still lacks. The biomedical handling of chronic pain keeps on being largely grounded on a conceptions which, far from approaching pain as an autonomous pathological phenomenon deserving a specific therapeutic management, sections patients' pains on the basis of their localization in the body. In this respect, fibromyalgic syndrome is emblematic since the presence of chronic and widespread pain in the musculo-skeletal tissue endorses this conditions' collocation in the rheumatologic field, even against strong evidence indicating that a much wider and comprehensive approach would be required.

Nevertheless, the investigation of the clinical handling of fibromyalgia in Rheumatology and the enquiry of the sufferers' experiences of illness has showed how the issue of the acknowledgment of chronic pain as a disease and the related matter of the divide between organic and psychological interpretations of chronic pain are much more complex. In particular, the dualistic conception of pain' causation

affecting biomedical framework appears to be due to practical issues instead than to a-priori conceptions of mind and body relations, such as the hyperspecialization of biomedical specialties and the consequent compartmentalization of the patients' distress. Moreover, the issue of the potential stigmatization of patients whose suffering is described as psychogenic and the related equation of psychogenic pain as "unreal pain", has showed to be also strongly bounded to practical matters. A cogent example in this regard is the interpretation of the comorbidity between chronic pain and mood problems and the management of painful conditions such as fibromyalgia with antidepressants. While the therapeutic aspect is usually approached by physicians as well as by patients in a pragmatic perspective, i.e. if antidepressants are beneficial, than they should be employed, the epistemological issue, i.e. how to conceive of the relationships between chronic pain and mood disorders, especially depression, marks a relevant divide between patients' and physicians'. Physicians present several conceptions of the pathological character of fibromyalgia and of the related mood disturbances, even if most of them recognize a prominent psychological characterization of this condition. On the other hand, patients usually consider psychological issues as the direct consequence of their pain, and, therefore, the majority of them do not take in account a psychological management of their condition since this would somehow entail a misrecognition of the reality of their condition, especially of their pain. In this sense, it is arguable that within biomedical knowledge, where both patients and physicians act, an appreciation of pain as a complex multidimensional entity and as a pathological

phenomenon in itself, still lacks. One of the main factors contributing to this matter of facts is the actual structure of the biomedical system, which does not allow for such an integrated approach to pain. Furthermore, pain's complexity, its being at the same time an emotional and a sensory phenomenon involving psychological as well as organic features, and an entity characterized by individual as well as social aspects, requires biomedical system solutions which are hard to be tackled without a wider reflection on the very foundations of this system and of its goals. The "fibromyalgia issue", i.e. the biomedical framework's inability to account for a suffering condition defined as of its pertinence, urgently calls for a further reflection of biomedicine on pain, and, more generally, on the solutions which biomedicine is able and willing to provide to human suffering.

As potential future development of my research, an investigation of the origins of biomedical system's structure and of its compartmentalization should be pursued by referring to the ways in which different sources of knowledge on suffering have emerged in the clinical practice in recent history. I believe an adequate analysis of this topic should pay much attention to the relationships between the so-called physical pain and mental pain, i.e. depression, and the ways in which biomedicine has dealt with them so far. Moreover, the link and the definition of the boundaries between these conditions would require further enquiries, especially with reference to the role played by the employment of antidepressants and of the market interests

behind them<sup>119</sup>. Another aspect tackled in my dissertation which requires further investigations is the definition of chronic pain as a disease in relation to legal and insurance contexts, especially in the light of techniques as the brain-imaging which promise to make us “see pain”. (See Camporesi et al., 2011)

Finally, a conclusive reflection on my work cannot but recall the research methodology employed. The choice to use several approaches, i.e. the history of ideas, the philosophical critique and the ethnographic analysis, has been considered the best way to grasp the different intersections characterizing biomedical knowledge of pain. The investigation of the ways in which different sources of knowledge in biomedicine connect, are integrated and clash with each other, has been pursued in a multi-level perspective aimed at reflecting the dynamic and multi-faceted character of “pain as the object of biomedical knowledge”. Moreover, adopting different views has implied also taking advantage of several tools of research, which have proved to be fruitful in the analysis of the various aspects of the topic of investigation. In this regard, the observation of the clinical interactions and the photographic enquiry on the sufferers’ experiences have provided to the theoretical analysis and its findings an integration and a reconfirmation. This is the reason why future reflections should consider the potential of combining speculative analysis with fieldwork investigations as mutually enriching, instead of mutually excluding.

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<sup>119</sup> On the relationships between drugs, society, and the classification of depression, see Ehrenberg, 1998; Barker, 2011 analyzes the crucial role played by pharmaceuticals approved, such as Lyrica for fibromyalgia in the acceptance of this condition)

Furthermore, the employment of visual instruments should be considered as a resource both for social scientists as for clinicians. (See Padfield, 2003) In my research, the photographic tool has showed to be particularly fruitful in the attempt to tackle those aspects of pain experience hard to be represented through the verbal language; moreover, the employment of pictures has led to the unraveling of aspects of the patients' experiences by the way of the metaphor, helping e.g., to elicit memories, impressions and feelings. (See Semino, 2012)





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