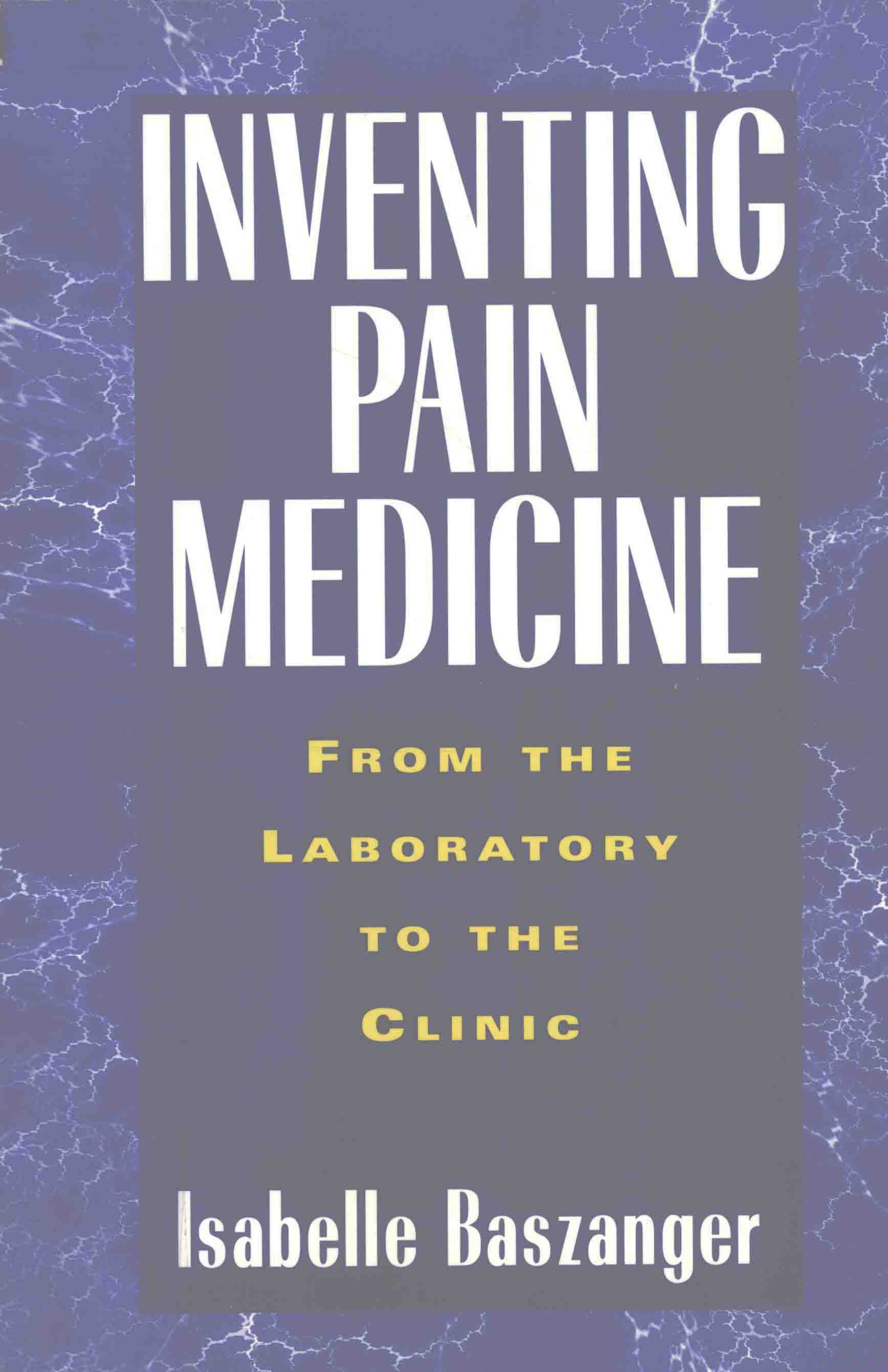

INVENTING PAIN MEDICINE

FROM THE LABORATORY TO THE CLINIC

Isabelle Baszanger

Inventing Pain Medicine

From the Laboratory to the Clinic

ISABELLE BASZANGER

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Inventing Pain Medicine

à Monique, sans qui je serais restée
au bord des mots et des idées

à Chloé, pour qu'à son tour
elle y trouve sa place

To the memory of John Liebeskind

> *Pain has an element of blank;*
> *It cannot recollect*
> *When it began or if there were*
> *A day when it was not.*
>
> *It has no future but itself,*
> *Its infinite realms contain*
> *Its past, enlightened to perceive*
> *New periods of pain.*
>
> —Emily Dickinson

Foreword

Pain is a popular subject nowadays. One need only open a magazine, turn on the radio or television to become aware of it. The message is: "Pain can be conquered!" It must, therefore, be combatted and its mysteries penetrated. Is this avalanche of articles and documentaries about pain merely a passing fad or does it reflect a real breakthrough? Does it reflect the emergence of a new relationship between pain and medicine? This question is at the heart of the work presented in this book. Although the merits—not to say the urgency—of this question are quite obvious today, this was not so when I began this study. I first became aware of the existence of a "pain clinic" in 1981 during a visit to a hospital in Canada. As a sociologist working in the field of medicine, I was immediately interested. Was this a unique, local facility or was it a sign of a new institutional development in the practice of medicine? As someone who has been subject to pain in her own life, I felt a mixture of curiosity and even hope to see physicians specializing in pain and according it a recognition equal to other medical problems. Upon returning to France, I was eager to find out more, and this turned into a research venture extending over several years. Pain medicine, in France at least, was in an embryonic state and was virtually unknown, so that, in a sense, my work and the field of pain medicine evolved simultaneously. Much has changed since then and the time has come to reflect on the early development of pain medicine and its future. First, however, we need to understand something about its origin and methods as well as the consequences for both physicians and patients. We must also try to understand how this new field affects contemporary trends in medicine more generally. This is the first aim of this study.

All research work is a collective undertaking, even if not immediately apparent, and my work is no exception. Through their unwavering support as well as their own research, Renée Fox and Anselm Strauss encouraged me to undertake and continue this work. But none of it would have been possible without the cooperation of the professionals in the field. I am indebted to the numerous physicians who agreed to discuss their work in depth with me, often more than once, and who replied patiently to even seemingly incongruous questions. I owe even more to the staff at the two pain centers I studied, who, stoically and for the most part with kind forbearance, accepted my extended presence. I thank them all most warmly and hope that, in return, they will find some interest in an outsider's critical view of their practice. Another vital contribution to this study was that of the patients themselves, who in the course of lengthy interviews attempted to unravel the threads of their pain and help me understand something of their relationship with pain medicine and pain physicians. I would like to thank each of them by name but must respect their anonymity. Over the many years spent on this work, I was fortunate to be able to rely on the intellectual companionship and nurturant friendship of Martine Bungener, Nicolas Dodier, and Emmanuèle Reynaud. They read the numerous versions of this work, commented on them, and are well aware of the many periods of discouragement that arose along the way. This book owes a great deal to them. Anne-Marie Guillemard's support accompanied me before I even undertook this research. I would also like to thank certain people for their comments on the first version of this work: Danièle Carricaburu, Elizabeth Claverie, Ilana Löwy, and Jean-François Picard. Some parts of this book benefited from my discussions with Adele Clarke, Joan Fujimura, David Silverman, and Lucy Suchman. I am grateful to Jean-Daniel Reynaud for his critical comments. Annie Quartararo and Julien Weisbein assisted with gathering some of the historical and bibliographical data. I would like to thank them here.

Finally, I must mention my meeting and correspondence with Professor John Bonica and my intense discussions with Roselyne Rey, both of whom left us all too soon. The contribution made by each to their respective fields marks a particular moment in the history of pain. This book is also for them.

The English-language edition would not have come about without the warm welcome and interest of Martha Heller at Rutgers University Press. She has been an understanding and efficient editor while this translation evolved. I am glad to thank her. The initial draft of the translation was prepared by Philippa Crutchley Wallis. Monica Casper went through the final draft and checked the technical terminology with a shrewd eye. However, accomplishing a translation calls for some extra dimensions among which are understanding and patience. I was lucky to find both—not to mention supportive friendship—in the editorial help and efforts of Charles Fredrikson and Brigitte Goldstein. They both gave generously of their time, making the translation process less painful for the author.

Contents

Introduction

"Fighting pain"—these words sum up a new imperative in Western medicine. A clear and pressing obligation that has, nonetheless, taken many years to filter into actual practice. It is evident in such programs as the World Health Organization's work on cancer pain and, at the national level, in the various directives and recommendations issued by health ministries in various countries. In France, for example, a circular letter of January 19, 1994, from the minister of health to regional and departmental managers of health and social programs, encouraged physicians "to make an effort to better fight pain." Given the close association between medicine and alleviation of pain in the history of medicine, it may seem surprising that we had to wait until the end of the twentieth century to see the concept of fighting pain defined as a priority. Surely, it was always a priority! And yet the experience of each one of us, either directly or through someone close to us, often indicates the contrary. Who among us has not, at some time in our lives, encountered the reticence of the medical establishment, or even a certain indifference on the part of physicians faced with a patient in pain? And yet, the fight against pain has always been seen as the raison d'être of medicine. In many different ways, it has always brought together, and still does, patients and physicians around the common goal of alleviating suffering.[1]

In view of the extraordinary medical achievement of controlling surgical pain by means of anesthesia and other advances in healing initiated by the therapeutic revolution that began in the nineteenth century,[2] one might have thought that pain should, if not be abolished, at least be always taken into account. In fact, this imperative is a rather new one. Until very recently, pain was seen as a necessary, if ambiguous, element in diagnostic work that tended to lose its clinical interest once it had delivered its message. It was supposed to vanish of its own once the illness or lesion associated with it was cured or had disappeared. Pain, in this sense, although known to physicians and nursing personnel, was not the real target of therapeutic intervention; its true value tended to be seen as diagnostic. Indeed, quite often, the pain caused by an illness was seen as the flip side of a coin, the price to be paid for the development of increasingly effective investigative and therapeutic techniques, which were of vital interest to both physicians and patients. Far from being a heroic new therapeutic frontier, pain was seen as a mark of the human condition. Pain was part of the struggle for survival, was seen as a normal companion to illness and aging, and although a handicap, it was not part of a specific area of medical activity. Pain was thus a shadow area of medicine, a blind spot in medical knowledge. The new imperative attempts to bridge this gap by bringing the problem of pain into the foreground. The history of this still fragile transition is at the heart of my book, and we will consider it by examining the innovative approach fundamental to it: the invention of pain medicine.

Pain Medicine: A Turning Point in the Relationship Between Medicine and Pain

The greater visibility of pain is largely associated with the development of a new way of understanding and treating the pain of individuals within the framework of a new institution, the pain clinic. In 1953, the American anesthesiologist John J. Bonica introduced the concept of "pain clinic" in a work devoted to "pain management," which he had started to put into practice as early as 1945. The idea is a simple one. It is based on bringing together a multidisciplinary team of specialists who would try to resolve complex problems of pain where ordinary therapeutic solutions had no effect, or, to put it more bluntly, had failed completely. Simple in itself, the idea nonetheless implied a radical change, directing medical action toward dealing with the pain itself and not only with its cause. On first sight, this may seem similar to the symptomatic approach so greatly stigmatized by the development of clinical, scientific medicine. To make pain the object of a specific and legitimate medical practice, justifying independent sites of treatment and specialized practitioners, it had to be endowed with unique characteristics that would give it a new status. This process was to take some twenty years and involved separating clinical pain from "laboratory" pain, and most importantly, separating chronic pain from acute pain.[3] It was only when this definition of chronic pain as a "state of illness" or "a disease in itself" had been established and specific medical practices had been proposed, that programs to "fight pain" in all its forms, as we see them today, could be put into effect.[4] In the meantime, pain medicine had become a reality with its own treatment facilities (pain centers and clinics), its own specialists (pain physicians, also known as algologists), specific practices with the primary aim of dealing with pain itself and a specific population of patients known as chronic pain patients.

This is the reality this book proposes to explore. The concept is now established, even if it will take some time for it to become integrated into everyday practice. Before 1960, there were only three "pain clinics" in the United States, including the first center set up by Bonica. Some faint traces of development can be found in the 1960s (we have no figures), but the movement gained real momentum after the first major pain symposium held in 1973 (see chapter two). A first census, published in 1977, lists 327 pain clinics, either simple clinics or multidisciplinary centers; 60 percent were located in the United States. In 1977, France had no pain clinics, but, as we shall see, it was at this point that some young physicians began to take an interest in the problem. An American directory of 1979 lists 428 "pain facilities" including 172 pain centers, that is, facilities offering all the necessary diagnostic and therapeutic resources. Estimates based on these figures indicate that in 1988 there were approximately 2,000 pain clinics, 450 of which were located in Europe, with an estimated 750 pain centers in the strict sense.[5] Even if these figures are not absolutely accurate (although they are the latest available), they do reflect a sharp growth, which is even confirmed by the rather scanty data we have for France. Over and above their comparative numerical value, the figures do testify to a change in the medical world's general interest in pain.

I shall approach the question of pain medicine by combining several registers of analysis that are often applied separately, primarily the historical and pragmatic perspective. By basing my analysis on the intersection of these two planes, I shall try to understand two things at the same time: how did the new conceptual and organizational forms of dealing with pain emerge at a given moment, that is, the invention of pain medicine, and secondly, what are the specific practices of medical work and of patients' work, that is, pain medicine in practice. I shall start with an approach that borrows its temporal perspective from history and its analytical framework from interactionist sociology to examine the origins and development of the movement that led to pain medicine in its current form.

Pain Medicine: A Historical Perspective

What motivates physicians to concentrate exclusively on pain? Alleviating pain is an obligation incumbent on all physicians, one of the components of the Hippocratic Oath. Medical students are taught the vital role of pain in indicating a lesion or a disease and how to distinguish between different types of pain, whether local, profound, perforating, and so on. They are also taught to see what might be behind a given pain. For example, pain in the right arm or even in the lower left jaw can indicate the onset of a heart attack; in other words, a problem may be located at some distance from the site of the actual pain. Students learn to respect this "vital symptom" which, along with other signs, guides the diagnostic approach toward a correct definition of the pathology causing the pain. Once identified, it will become the target of therapeutic action. In theory at least, pain should disappear once its cause has been treated. Medical manuals emphasize the importance of pain as an element contributing to diagnosis, but it is almost totally neglected once they move on to the therapeutic stage.[6] However, some pain persists for a long time after the cause has been identified and appropriate treatment has been applied. In other cases, the etiology remains obscure or even unknown; in still others, it accompanies the evolution of a disease that has been duly identified but for which there is currently no treatment. This has long been the case. In a sense, these different types of pain constitute a sort of residual category of medical practice, which, until recently, did not require a specific treatment but called on the physician's compassion—often very real but also often quite inadequate because of heavy workloads and other pressing problems.

This situation began to change by the end of the Second World War, thanks to the action of some people who initially worked in great isolation. After enrolling a few of their colleagues in the movement, they very gradually brought about a change in the status of pain, defining it in certain specific circumstances as "a disease in itself." While working to define this new entity, they claimed a specific approach based on a particular specialization and independent medical practice. They thus opened within the medical profession a space for the new professional category of pain physician, and offered certain patients a resource that had not existed until then.

We first must seek to answer such questions as: When, that is, at what point did the transformation in the way of looking at the question of pain in medicine actually begin, and why? What were the factors contributing to this change in the way of looking at the problem? Who were the people who originally made the medical world aware of the problem, who began to imagine—and at the same time began to experiment with—possible ways of dealing with pain, then, after conceiving of a project, tried to communicate it to a larger group of people? How did the processes whereby these changes took place work, that is, what are the conceptual, organizational, and institutional elements, both in the medical world and in society at large, that encourage, accompany, or hamper the actions of these "entrepreneurs," and what resources are available to them?

Here we shall try to understand the overall movement of the creation of pain medicine, the development and stabilization of the concept of a "pain clinic," on the one hand, and the development and stabilization—difficult, as we shall see—of chronic pain as a new object for medicine on the other. I use a sociological perspective based on professional segments and social worlds[7] which views the medical profession as a heterogeneous world that is constantly changing and is made up of segments, each of which encapsulates different conceptions in terms of the specific features of their practice and their main activity, and at the same time reflects different identities—segments that are formed, maintained, and eventually developed until they become a new specialty and/or disappear.[8] Such an approach is particularly relevant for this work, given the emergence within the medical profession of a small group of professionals—a segment—who are working to develop their own specific conception concerning ways of understanding pain and its treatment and are thereby creating a specific identity for themselves, one of pain physicians. Particular attention must be paid to the period in the arduous process out of which pain medicine developed into a medical specialty that might be described as "phase of stagnation." Although the project was almost abandoned then, from a sociohistorical point of view, this prolonged period is particularly interesting since it forces us to analyze how the stagnation was finally overcome. Here, the conceptual imagery of social worlds, which expands the framework of professional segments,[9] will allow us to go beyond the limits of medicine *strictuo sensu* in order to analyze the mechanisms through which a world of pain was constituted in which practitioners from a wide variety of professional backgrounds (e.g., clinical medicine, basic research, psychology) were brought together. This world—it is my hypothesis—was to serve as a basis for certain actors to ground and validate a still embryonic pain medicine.

The examination of the gradual creation of a model of pain medicine will be followed by examining how pain medicine takes shape and root in a given country. How, within a specific national, medical environment, a group of physicians emerges that seeks to construct a new form of practice around the treatment of pain. I shall focus on France, where pain clinics first emerged in the late 1970s, in the wake of the organization of a world of pain between 1973 and 1975. Returning to my approach based on professional segments, I shall describe the birth of pain centers in France. Who were the main actors? Where did they come from? How did they first encounter the problem of pain and how was their initial interest transformed into more specific commitment to creating facilities where pain could be treated, first unofficially, then advancing toward greater visibility and legitimacy? I shall trace the process whereby isolated actors began to acknowledge each other and, weaving a common identity, attempted to construct boundaries for their small group around a unified definition of the core object of their practice. Then I shall study the mechanisms underlying the constitution of a group of pain physicians with particular attention to the way in which the idea of pain clinics was put into practice and to the technical possibilities associated with the conceptual reference of the first model of pain medicine.

A central focus of my probe is the operationalization of theoretical knowledge, a common aspect in the emergence of a new professional segment. This aspect has been largely neglected in research, which thus far has focused more particularly on the practice of existing segments.[10] We shall see how the gradual formation of a group of pain physicians, while starting from a common point of departure—the initial formation of the model of pain medicine and its underlying scientific theory—was also, from the outset, built around important differences in the way the various actors applied this theory and its technical possibilities. The emerging movement led to the simultaneous development of two standard arrangements for dealing with pain, which differ both in terms of their organizational mode and in the techniques used, and which are based on contrasting definitions of chronic pain and pain medicine. As we shall see, these arrangements correspond to two different conceptions of the medical clinic. The first approach, whose aim is curing pain, uses the traditional tools of the clinic to distinguish between physical pain and psychic pain. The other, which aims to manage pain, transcends the distinction between physical and psychological pain and focuses more directly on the patient's experience of pain and tries to modify it.

The study of this heterogeneous development within the framework of a single innovation leads to a very different understanding of pain and the patient, in other words, the disease-physician-patient configuration. This discrepancy compels us to take a close look at the way in which certain types of historical research analyze longitudinal developments in medicine, and challenge some of their conclusions. The works of David Armstrong and of Arney and Bergen,[11] following Foucault,[12] present a new stage in the development of medicine, based on a reconstruction of "the patient's view." These studies show how from the clinical model, as reconstructed by Foucault, a new "medical gaze" (starting around 1950) is being structured that is gradually modifying the place occupied by the patient and accords greater importance to the patient's "subjective experience"—less in terms of a new humanism than as "a technique demanded by medicine to illuminate the dark spaces of the mind and the social relationships,"[13] which expanded the physician's overall vision. This very rich vein of sociohistorical research clearly demonstrates a change in the way of conceiving of the clinic, which transforms "the meeting between doctor and patient (that was no longer) between an inquiring gaze and a passive object but an interaction between two subjects,"[14] who are defined as partners in "a joint venture."[15] This change is presented as marking a sudden divide in the history of medicine, defining the terms of a new "code of perception," a new "episteme," that very gradually arouses the interest of medicine as a whole. In both cases, the proposed model of analysis involves different stages that represent so many milestones in a given period. Here, we also encounter other well-known bodies of research by medical historians, based on different theoretical premises, such as Ackerknecht's,[16] which distinguish between different types of medicine (patient's bedside, hospital, laboratory), first defined by Jewson[17] as cosmologies associated with specific, successive, and exclusive modes of production of medical knowledge.

It is precisely this development in successive stages that is called on by a historical approach to pain medicine, the emergence of which entailed the coexistence of two different models at the same time. As mentioned above and will be seen in detail later, two approaches to chronic pain derived from a single theoretical foundation: one reads pain in the body and can be seen as belonging to the clinical model described by Foucault; the other reads and listens to pain through the patient's experience and seems to correspond much more closely to a new kind of logic. In his conclusion, Armstrong refers to the coexistence of medical practices based on these two historically distinct codes of perception, one now outdated and the other more current: "The message behind this new perception does not necessarily have immediate or real effects on clinical practice . . . most clinical practice today—particularly in hospitals—is undoubtedly based on a much older interpretive scheme. Any tensions . . . are due to a fundamental conflict between the theoretical level and concrete experience."

This explanation, which implies a uniform change at the theoretical level accompanied by a very slow application in practice, is not very enlightening for our purposes. We are dealing with an innovation based on a central theoretical nucleus separated, in terms of practice, into two distinct forms, of which each represents a new way of understanding chronic pain. The coexistence of different models would tend to suggest a development of medicine that is taking the form of a continual integration of ways of thinking and acting, an "active sedimentation" of conceptions of the clinic rather than their disappearance one by one. Here, I draw on the work of John Pickstone,[18] who makes the case for a typological model rather than a staged model as a frame for the historical analysis of medicine. As we shall see, the very complexity of his model makes it more effective than a genealogical one in illustrating the heterogeneous nature of medicine. However, I believe that we shall gain a fuller grasp of the dynamic process of an innovation if we combine his model with a pragmatic, microsociological analysis of medical work, thereby adding to the historical vision of the development of medicine yet another lens, namely the sociological.

Pain Medicine: A Pragmatic Perspective

MEDICAL WORK

In a sense, my research could end with the history of pain medicine. However, I find it impossible to stop at that point; I want to understand what happens when these conceptions are actually applied in practice. To the historical approach to pain medicine, I add a pragmatic perspective of medical work in practice. The focus of my questions, therefore, must be able to shift: here, the work of the actors over the long term; there, the actors (physicians and patients) in their everyday routine. My method of collecting information changes accordingly: gathering data from the literature (books, scientific journals, statements in specialized and mass-market media, minutes of working groups) or in interviews with physicians at pain centers is now accompanied by ethnographic observations of clinical procedures at two pain centers, chosen for their representativeness of the two major conceptions of pain medicine.

Following the pragmatic tradition of sociological research, my aim is to study medical practice in its day-to-day operation, to go beyond mere discourse, and to seek to understand what pain physicians actually do and how making persistent pain the object of their intervention eventually alters medical work itself. Chronic pain is a problematic subject for at least two reasons. First, pain is a private, personal experience which no other person can tap directly. Hence, the act of conveying it to another person inevitably involves relying on the subject's own words. In this sense, it is a medical object quite distinct from those that can be directly read from the body or discovered through laboratory tests. Second, in the case of chronic pain, the persistence, which is the result of medical failure, challenges the validity of explanations given by the main actors, lay persons, or medical personnel—along with their actions, past or to come. Because it is a private sensation that, in the last resort, cannot be objectified in any way, pain cannot easily be stabilized as an undeniable fact to be used as a basis for professional practice and for the relationship between professional and lay persons.[19] On the contrary, I believe that the fragility of pain as fact has a significant effect on medical practice and should, in particular, accentuate the "deciphering" work carried out by any physician faced with a new patient. This initial difficulty makes pain a very useful object in a sociological study of medical work, especially since—as my analysis of the process of the emergence of pain medicine, particularly in France, will show—this difficulty is reinforced today by the absence of a unified concept of chronic pain to which physicians can refer in order to characterize a patient's pain situation.

This dual obstacle affects the day-to-day practice of physicians and their relationship with their patients. It forces them to use the transient data patients contribute to carry out work that will eventually generate something they can call chronic pain. This is an aspect I am particularly keen to examine: How does the physician decipher the patient's pain to organize the course of action to take? How do physicians make use of the scientific and technical resources available to them in the course of their intervention? Given that the very object of medical intervention is pain, which is linked directly to the patient (who literally "owns" it), how does the physician handle this experience in medical work? Listening to patients, treating their words as sources of information, as a vital element in the "reality" of this pain, a guide to action, these are the decisions that require not only the application of a body of theoretical knowledge but eventually a professional construct as well. Integrating this wealth of resources into actual practice is one of the primary facets of medical work. One of my objectives is to analyze the way in which these resources, garnered from different areas of knowledge and from the patients themselves, are mobilized by physicians to formulate a judgment concerning the cases of chronic pain they must treat. At this point a clear connection can be discerned between the longitudinal and the pragmatic perspective. Since it shows, from a historical point of view, how a model of pain medicine branches off into two very different directions when it takes root in a particular country, we can examine, from a pragmatic viewpoint and taking advantage of this situation of innovation in which practices have not yet jelled into routine, a vital but often neglected dimension of medical work, that of operative knowledge. How is this knowledge constituted in practice, or to put it differently, how, with respect to their patients, do physicians put together the practical arrangements of theoretical facts that constitute a body of resources allowing them to structure their intervention?

My analysis of the relationship between context of knowledge, constitution of a body of operative knowledge, and action applies to a hitherto neglected area, a current sociological approach that utilizes detailed ethnographic surveys to examine the ways physicians in specific medical fields form judgments, make therapeutic decisions, and categorize sick persons. For example, within a pediatric cardiology unit and surgical clinic for children with cleft-palate and harelip syndrome, David Silverman[20] systematically explores variations in the physician-patient relationship in the type of consultation and decision-making models physicians use. He identifies three models or formats: the medical decision-making model, the persuasion model, and the democratic model. To these he adds a consumer model that can be found in certain consultations with adolescents suffering from harelip syndrome, when decisions about recourse to cosmetic surgery are made. Similarly, in his study on exercising judgment in the case of occupational medicine, Nicolas Dodier,[21] referring to the concept of "frame" as used by Goffman,[22] analyzes how physicians, when confronted with individual complaints, may act in accordance with two major "frames" of a vastly different sort.