Doctors and Patients: History, Representation, Communication from Antiquity to the Present

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To the memory of Doctor Goffredo Malatesta, my father

Doctors and Patients

History, Representation, Communication from Antiquity to the Present

Edited by Maria Malatesta

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Introduction

Doctors and patients between historiography and medical humanities

Maria Malatesta

The relationship between doctor and patient is a historical construct that has acquired highly complex features of interdependence over time. Doctor and patient, together with the illness, constituted the sides of the Hippocratic triangle; but for centuries their relationship was not exclusive: numerous actors populated the world of health care, and decisions by the sufferers to rely on the care of doctors depended not only on the social and cultural environment surrounding the patients, but also on how medical authority was perceived. The conquests of medicine and advances in treatment methods, the professionalization of doctors, changes in the social system, culture, and expectations impacted on what was only apparently static relationship, changing its features. Today. the relationship between the doctor and the patient is no longer defined solely in relation to the illness as it was in the past[1] but also with reference to care, health and its maintenance.

The history of medicine for long failed to consider both the mutability that characterized the doctor/patient relationship over the centuries and its instability due to power dynamics whereby one party to the relationship sought to control the other. There are various reasons for this neglect. The first is the fact that the sources on which the traditional history of medicine was based had for centuries been produced mainly by doctors. By writing treatises on medicine, doctors established the coordinates on which representation of their relationship with patients was constructed and then handed down over time. From the classical age to the nineteenth century, the discourse of doctors and philosophers regulated the relationship with the patient by means of rules whose main purposes were to strengthen the doctor's still weak image and to give him legitimacy in society. The canons thus established fixed the structure of the doctor/patient relationship. They transmitted the idea that the relationship was governed exclusively by the ethical principles on which the medical profession had been founded during the classical age, and which could be taken as given in medical culture and practice.

In an address of 1900 to a French conference on medical ethics, Professor Grasset declared that the duties of doctors towards patients were "known and followed." But work was required on the relationships among doctors, the rules on which had yet to be developed and introjected.[2] In a period when the professionalization of medicine was almost complete in France and the other Western countries, and when medical monopoly had been achieved almost everywhere,[3] the fundamental problem perceived by the medical class concerned the relationships among professionals, whilst those with patients were no longer considered a matter for discussion. The history of medicine long cleaved to a similar position. Until the second half of the twentieth century it was written mainly by doctors who privileged a iatrocentric narrative internal to their profession which extolled the achievements of science and the great physicians. It was a history written from above and populated with heroes. It paid no attention to the social aspects of health and disease, and even less to the experiences of patients. The latter were considered solely from the point of view of the ethical code which doctors had been obliged to follow since the age of Hippocrates.

During the 1960s, research in the humanities and social sciences made it possible to take a different approach to the history of medicine. Keir Waddington has reconstructed the development of the social history of medicine according to generations. In the 1960s and 1970s, there arose a generation of historians interested in how the general social, economic, professional, and cultural context influenced medicine. Then, in the 1990s, the next generation of historians took up the challenge of cultural studies by extending their research fields and expanding the definition itself of the social history of medicine to encompass the study of how society influences medicine and vice versa.[4] As a result of this historiographical revolution, the history of medicine has become increasingly the preserve of professional historians, while doctors have lost the monopoly over the discipline that they enjoyed for centuries.[5] The traditional iatrocentric perspective has been ousted by a bottom-up approach intent on grasping the multiple relationships between medicine and society. This approach considers the emotions of individuals in response to sickness and death,[6] their representations, gender relations, disease, and care institutions.[7]

The historiographical revolution has intersected with demands by certain segments of medicine that, since the 1960s, had expressed the need for a social, demographic and cultural history which granted patients a place hitherto denied to them.[8] This encounter led to a closer focus on the concrete actors of the history of medicine, and the relationship between doctor and patient moved onto the agenda of historians. Still in 1999 Mary Lindemann complained that many of the promises of the new medical history had not been kept: it remained predominantly an English-speaking discipline and had not been extended in its chronological and geographical range.[9] Sixteen years later, it can be said that a significant number of the intents of the new medical history have been fulfilled, and that the change of perspective has concerned in particular the relationship between the doctor and the patient, which is now studied across a pluri-millennial time span and relatively to several countries. The argument is fraught with difficulties from the methodological point of view. As recently noted by Joël Coste, the prime problem concerns definition of the subject of research, which is not the relationship of the doctor and medicine with society, nor that of individuals with the doctor and medicine, but rather the relationship that arises in the specific context of the illness. There is also the risk of lapsing into anachronism by projecting into the past issues that pertain to the contemporary debate.[10] But the main difficulty concerns the sources to be used to reconstruct the relationships among patients, doctors, and the many actors that animated the healthcare scene until the twentieth century in specific historical and cultural domains.

Historiography on the doctor/patient relation is indebted to the discovery of new sources, or the reinterpretation of traditional ones, for information on patients and their relationships with disease and doctors. Historians of the ancient Greek and Roman world have drawn on archaeological documentation and newly-discovered epigraphic and papyrus sources – the latter from ancient Egypt – to investigate the medical marketplace of the ancient world in different light, considering not only its complexity but also the ties among the various kinds of medicine. For the mediaeval period, besides the *consilia* – the written diagnoses compiled at a distance by university doctors whose use began in Bologna in the thirteenth century and then spread to France in the fourteenth – particularly fruitful are such not directly medical sources as wills and the correspondence exchanged by a patient's family members. Inquiries by historians into these sources have redeemed the figure of the mediaeval patient[11] from the darkness to which it had been consigned by a traditional historiography more interested in the philosophical and ethical aspects of the doctor/patient relation, and with particular regard to its mercantile and monetary components. Especially in regard to the modern age, the written consultation – compiled in almost identical form until the nineteenth century – has proved valuable for reconstructing the everyday practice of the doctor/patient relationship and the familial and amical setting in which it was embedded.[12] Besides the written consultations, the letters sent by patients to their doctors have furnished historical information with which to reconstruct the network of social relations to which the patients belonged and which conditioned their relations with the doctor.[13]

The extension of historical research and the use of new sources have also made it possible to question some of the central tenets of the historiographical revolution. Foucault gained many followers in the field of historiography with his theories on the advent of hospital medicine and the consequent disciplinary effects that gave rise to a doctor/patient relationship based on domination and alienation.[14] Nevertheless, drawing on thorough research, some historians have rebutted these claims by showing that they were not generalizable to all contexts, and that they anticipated phenomena that pertained to the twentieth century. Anne Digby was one of the first to question the periodization introduced by Foucault and which was then applied to the English-speaking countries by Ivan Waddington.[15] By consulting a variety of institutional and private sources, Digby showed that hospital medicine did not arise in England until the beginning of the twentieth century, and that hitherto the practice of medicine had been characterized by traditional home care. She also showed that nineteenth-century English doctors had very little influence over their patients, mainly because of the poverty of the latter and the persistence of traditional cultures that directed them to healing methods alternative to scientific medicine.[16] Research by a group of French historians headed by Jean-Pierre Goubert on *consultations medicales* in France of the eighteenth and nineteenth centuries, the period which, according to Foucault, saw the birth of the clinic, has cast doubt on the assumption that the latter gave rise to the domination and alienation characteristic of the modern doctor/patient relationship based on specialization and exploitation of the sick body for the purposes of medical progress. The *consultations medicales* furnished no evidence in support of Foucault's thesis; on the contrary, they revealed the existence of conduct autonomous from the doctor by patients whose class was no longer solely the aristocracy but was diversifying considerably.[17]

Dora B. Weiner's reconstruction of the healthcare system during the French Revolution does not evidence features of discipline and authoritarianism; rather, it highlights the dynamic and constructive relationship that arose in those years among patients, doctors, and the state. On investigating the case of the deaf, the blind, and the mentally retarded, Weiner emphasised the mutual exchange that took place in that period between people with disabilities and doctors. The former gave decisive assistance to medical science in its development of new methods of communication and care; the latter supported the revolutionary government in its endeavour to give patients citizenship and inclusion in the political and social system through the creation of a new system of rights and duties.[18] Study of tuberculosis patients instead induced Claudine Herzlich and Janine Pierret to describe the nineteenth century as a long period traversed by forces which generated the physiognomy of the modern patient. Two opposing tendencies centred on tuberculosis: one considered the disease to be a form of social collective belonging; the other saw it as a reason for stigmatization and expulsion from society.[19]

Not only have historians deconstructed Foucault's paradigm; they have disputed other interpretations propounded by pioneers of the historiographical revolution and which have impacted profoundly on the collective imagination. It was above all Philippe Ariès who fostered the myths of the 'good death' and the more human relationship with suffering purportedly distinctive of past centuries,[20] as opposed to the loneliness and alienation characteristic of modernity. Jason Szabo's research on death and incurable diseases in nineteenth-century France has deconstructed the romantic image of death. It has shown that when medicine could no longer provide support, chronic degenerative diseases were tragedies for which doctors tended not to accept responsibility.[21]

Despite historical studies concentrating on particular periods and countries, no comprehensive account of the doctor/patient relationship has been produced. It was not until the 1980s that two works devoted to this subject appeared. *Bedside Manners*, written by the medical historian Edward Shorter, was published for the first time in 1985.[22] It represented historiography's response to the sociological analyses of the 1970s which had denounced the medical profession's loss of authority and power with respect to patients, healthcare facilities, and insurance schemes. In his book, Shorter addressed the question of the doctor/patient relationship while studying how the medical profession in the United States and Britain had changed from the eighteenth to the twentieth centuries. He derived a periodization whereby the phase of traditional medicine concluded in the 1880s, when there began the golden age of modern medicine which ended in the 1950s. American doctors, who in the 1800s received only rudimentary training (and were consequently not comparable to the French and German clinicians), gained prestige in the late nineteenth and early twentieth century when also in the United States the scientific revolution led to the generalized introduction of university degree courses in medicine. The professionalization of medicine gave doctors the social recognition which they had previously lacked, and it increased their authority over patients because they could use new diagnostic and clinical instruments. Foucault blamed the advent of clinical medicine for the depersonalization of medicine. Shorter, by contrast, argued that the doctor/patient relationship had reached its maximum intensity between the end of the nineteenth century and the first half of the twentieth. The scientific revolution had given patients complete confidence in the ability of the doctor and this made them amenable to medical authority. The medical patriarchate was thus an instrument with which to run modern medicine and to enhance the effectiveness of treatment. In the absence of today's diagnostic instruments, the doctor's listening to the patient's account of his or her illness could make the symptoms disappear. According to Shorter, the second scientific and pharmacological revolution in medicine that occurred during the 1940s and 1950s was the origin of the loss by doctors of the art of healing that was reflected in their authority over the patient and the trust of the latter.

Jay Katz's book, *The Silent World of Doctor and Patient*,[23] first published in 1984, argued in opposite manner to Edward Shorter. Katz, a jurist, reconstructed mainly in light of the rulings by the US courts the emergence of the concept of informed consent and its application in the medical field. The study was part of a long-period survey from the classical age to the twentieth century. Katz argued that since antiquity the power relationship between doctor and patient had been based on the patient's total exclusion from the decision-making process, so that it was the doctor alone who decided the care. This power relationship had remained unchanged until the end of the 1900s. The obligation of informed consent introduced in all the Western countries had not served – according to Katz – to build a relationship based on dialogue and mutual exchange in which the patient participated equally with the doctor in the therapeutic decision.

Neither the studies by Shorter and Katz – despite the wide use made of them by historians and social scientists – nor subsequent historiography have been sufficient to give the doctor/patient relationship an 'official' place in the history of medicine. The two collective works that today represent the most updated and sophisticated syntheses of the history of Western medicine from the methodological point of view deal only marginally with this theme. In *The Western Medical Tradition*, specific treatment of the subject is devoted to analysis of the factors that changed the doctor/patient relationship during the last decades of the twentieth century. The general rise in education levels, paralleled by the development of universal health care and technological medicine, increased the expectations of patients. The growth of individualism and awareness of rights strained the relationship with the doctor. And the growing influence of the media led to public knowledge of all malpractice cases, further eroding the confidence of patients in their doctors.[24] In the *Companion Encyclopedia of the History of Medicine*, discussion of the issue was entrusted to Edward Shorter, who re-proposed the thesis and the periodization (eighteenth-twentieth century) developed in *Bedside Manners*.[25] In *An Introduction to the Social History of Medicine*, Keir Waddington addressed the topic only in regard to the modern age and the nineteenth century, discussing the doctor's authority over the patient and the impact exerted on the latter by the birth of the clinic. Waddington's interpretations were intended to correct extreme judgements formulated in historiography in previous decades by emphasising the existence of an exchange between the doctor and the patient, and of negotiation mechanisms which restored balance to their relationship[26].

Historiography's new interest in the doctor/patient relationship has arisen in parallel with a movement which began in the Anglo-American countries and then developed in the medical field and in the humanities. Medical/health humanities have become an intellectual field in the sense given to the expression by Pierre Bourdieu: an area traversed by multiple trajectories and animated by a plurality of actors in constant tension with each other.[27] Medical/health humanities represent a cultural change of great importance because they have brought the doctor/patient relationship back to the centre of the scientific debate. At their basis medical humanities is a concern to recast the doctor/patient relationship by reactivating or enhancing the discursive and communicative components that modern medicine – based on objective and statistically significant data – has neglected on the grounds that they are irrelevant to the efficacy of care.

The sectors of medicine that have shown interest in the medical humanities have done so for eminently practical purposes. The humanities, in fact, are considered useful means to improve the training of future practitioners. They have been included in the curriculum of the health professions in order to enhance sensitivity to patients by means of multidisciplinary training. Narrative medicine has been one of the main innovations within this educational project. This current of studies arose in psychiatry and medical anthropology,[28] but it has become a field with its own autonomy through the work of the physician and literary scholar Rita Charon. At the centre of the theory that Charon has developed since 1986 is the narrative recounted by the patient to the doctor, who seeks to understand its significance from the clinical and affective points of view. But narrative knowledge does not consist solely in the doctor's capacity to attune intellectually and empathetically with the patient's story; it also requires self-reflexivity on the part of the doctor. From the perspective of narrative medicine, narrative, listening, understanding and self-reflexivity are the elements with which to construct a new alliance between doctor and patient and to found a new medical ethics.[29]

The field of medical humanities is not constituted solely by the theories and practices applied in the training of doctors. It also comprises, as T. Jones, D. Wear and L.D. Friedman write, "the intellectual practice of the humanities, which enables and encourages fearless questioning of representations of caregivers, and patients in all their varieties, challenges abuses of power and authority, and steadfastly refuses to accept the boundaries that science sets between biology and culture."[30] It is a mobile field with porous borders penetrated by the influences of cultural studies, media studies, post-colonial studies, and disabilities studies. According to the above-cited authors, it must now expand further to encompass all health professions, patients, and informal caregivers. The new definition of health humanities opens up avenues for research extending beyond the individual's experience of sickness and health and using a broader approach that also considers the roles of the community and public policy.

Perhaps because history has been the most traditional area of encounter between the humanities and the medical sciences, it is not considered today a core discipline in the medical/health humanities, which are decidedly centred on the dimension of the present. Yet the shift in historiography towards the social and cultural history of the body, disease, care, and healthcare institutions has substantially increased its capacity to converse with the disciplines and practices that make up the field of the medical humanities.

Doctors and Patients. History, Representation, Communication from Antiquity to the Present is a book planned within a university department of history, and it bears the imprint of those origins. The book's prime objective is to reconsider the possible contribution of the historical disciplines to clearer understanding of the processes investigated by the medical/health humanities by having the former converse with research today considered to pertain specifically to the latter. To this end, it has been decided that the book's unifying theme should be the doctor/patient relationship. From this ensues a second objective: to achieve a far-reaching reconstruction of the doctor/patient relationship from antiquity to the present day. The book is divided into two parts. The first, consisting of chapters written exclusively by historians, surveys the history of the doctor/patient relationship in Europe from the Greek and Roman world until the nineteenth century. The second part – to which historians, doctors, anthropologists, and scholars in media studies have contributed – covers the time span from the second half of the twentieth century to the present day, and the geographical area that extends from Europe to the Middle East. It consists of new research which rotates around the themes of communication and representation.

The four chapters that constitute the first part of the book primarily deal with the long period in which the medical profession was in search of definition, legitimation, and recognition. The prehistory of the professionalization of the medicine was notoriously marked by a structural weakness of the healthcare field due to the interweaving of five factors: the backwardness of the medical 'art', which laboured to turn itself into a science; the scant remedies available for health care; competition among the diverse practitioners that populated the field; and a small clientele. These factors impacted on the relationship that doctors had with their patients and on how the profession was exercised. This first part of the book yield better understanding of the components that from the ancient world have defined the doctor/patient relationship, and of how the latter has gradually evolved as medicine, cultures, and society have changed.

Going beyond a division frequent in historiography, the first chapter written by Daniela Rigato considers both the Greek and Roman worlds in order to determine the joint dimension along which the doctor/patient relationship unfolded in the two civilizations. In the Greek world, marked by a tripartition among divine or templar, scientific, and magical-popular medicine, the development of scientific medicine came about through a process of cultural cross-fertilization with divine medicine. The Hippocratic doctors rendered honour to the priests of the god Asclepius, while temples were the first public sites of scientific medicine. The coexistence of the two medicines fostered the practice among patients of choosing between appealing to the god or resorting to a doctor. If they chose the former option, they bargained with the divinity on the tribute due, which they paid only in the case of recovery. The bargaining principle also entered Hippocratic medicine, but in this case solely to protect the doctor. The latter stipulated his fee before the diagnosis in order to forestall accusations of having made a grim prognosis solely in order to increase his emolument. Hippocratic medicine thus produced a culture defensive of the doctor's interests by dictating the rules with which to comply when informing the patient: if the prognosis was ominous, it nevertheless had to be communicated to protect the doctor from accusations of homicide. In comparison with Greek medicine, Rigato valorizes Roman medicine, often considered to be only a sequel to the former. The introduction of Greek medicine in Rome took the typical form of a cultural transfer. The Greek doctors came to Rome as slaves, and they brought with them their culture, which they strenuously defended by continuing to speak and write in Greek. The resistance of the Roman elites to this contamination determined the marginalization of doctors within Roman society until the imperial age, when they began to enjoy privileges comparable with those accorded to doctors in the Greek world. The recasting of Greek medical culture in the Roman world produced significant changes in the relationship between the doctor and the patient. Rigato's essay stresses the cultural turn produced by the emergence of the *medicus amicus* driven by compassion (in the sense of sharing) for the patient's suffering. The change with respect to the Greek canon is especially visible in the behaviour of doctors with incurable patients. Despite state regulation of the profession during the republican age, some Roman doctors chose to treat severely ill patients, thus assuming the risk of being punished for the commission of errors.

The essay by Tommaso Duranti belongs within the branch of historiography that has disputed the idea that the mediaeval medical field was characterized by the figure of the philosopher doctor – highly educated but devoid of practical experience – for whom the patient was an object of speculation and gain, but not of care. It has instead been shown that from the early Middle Ages onwards a dynamic relationship arose between the doctor and the patient. Adopting this interpretation, Duranti reconstructs the emergence of the patient as an actor, situating him within the encounter between classical medical culture and Christianity. The universities were the forgers of this cultural change, whose effects reverberated on the doctor/patient relationship. Compared with classical medical culture, that of the Middle Ages placed greater emphasis on dialogue with patients, not only for anamnestic purposes but also to convey the doctor's interest in them. Galen had already suggested that the doctor should use terminology familiar to the patient. Certain mediaeval doctors like Alderotti gathered these ideas neglected by scholastic doctors to highlight the importance of narration for the purposes of medical care. Trust became the pivot of this dialogic relationship. In the classical and early mediaeval periods, obedience was considered to be the prime virtue of patients generally regarded as hostile to the doctor and recalcitrant to his instructions. The scholastic medicine that spread through the universities during the late Middle Ages wrought a cultural change of great importance: trust in the doctor was now considered to be the pivot of the clinical relationship. Duranti stresses that this extolling of trust by medical treatises of the time is a further indicator of the disobedience of patients; but he also believes that the obedience/trust dynamic exhibited an active conception of the care relationship in which the patient was perceived as an actor on a par with the doctor. During the Middle Ages, the doctor/patient relationship took the form of a contract, primarily moral but also material. The 'recovery pacts' both represented a system of guarantees for patients at a time when there were no rules on entry to the medical profession and evidenced the difficulties of doctors in gaining recognition of their therapeutic action. In the late Middle Ages, the doctor/patient relationship was set on more professional bases. Thus apparent was the contrast between, on the one hand, the egoism of the doctor inherited from the classical age and oriented to protecting his interests and asserting them in regard to the patient; and on the other, the altruistic behaviour predicated on the new Christian ethics. The dilemma of the terminally ill represented a clash between the two cultures. It also highlighted the gap between theory and practice, as evidenced by those doctors who were willing to treat plague victims.

The third chapter written by Claudia Pancino reconstructs the therapeutic scene from the fifteenth to the eighteenth centuries. Like its predecessors, it pays close attention to the sources from which it is today possible to gain a detailed picture of the doctor/patient relation during the *Ancien Régime*. The sources divide among three genres: treatises on popular errors in medicine, handbooks on medical etiquette (*galatei*), and correspondence between doctors and patients. These sources have mostly been used separately by historians and only in regard to certain periods and areas. Pancino considers them jointly and with reference to France, Britain and Italy. For the first two countries she takes account of the most recent historiography; whilst for Italy she uses texts on popular errors and *galatei* little or not at all known to Italian historiography. These two types of sources pertain to the genre of prescriptive and defensive literature characteristic of an age when medicine was in search of legitimacy and protection. Such literature had two purposes: to enhance the doctor's dignity by helping him to correct errors that he may have committed; and to codify patterns of behaviour intended to win the patient's trust and increase the doctor's social and scientific credibility. In the second half of the sixteenth century the doctor's status tended to be defined by the quality of his training and his therapeutic results; but still current was the cunning rhetoric that since the Middle Ages had been one of the components of defensive medicine. The old canons of the doctor's cynicism and ruthlessness were still considered legitimate, and indeed desirable; but the altruistic principle gained ground, and with it the idea that the duty of the physician was to treat the incurably ill, not to avoid them. The letters that doctors exchanged with educated and affluent patients and the medical treatises are sources that illustrate persistences and changes in therapeutic practice during the *Ancien Régime*: traditionally consisting of a doctor who treated a male patient, it remained unchanged until the eighteenth century. Yet the sixteenth-century medical treatises already manifested attention to the female body and its diseases. The scientiphic studies reverberated in professional practice, and in the eighteenth century doctors began to appropriate practices traditionally the prerogative of female practitioners and conducted gynaecological examinations. Like women, also children became patients after medical science turned its attention to them as well. The enlargement of the therapeutic domain enhanced the credibility of the educated doctor, who became an everyday figure in whom educated and affluent families placed their trust.

Historiography has reconstructed the centuries-long emergence of the patient as a subject and his/her conquest of citizenship in regard to the doctor and society as a whole. Granting of the right to informed consent was the act by which the patient-citizen acquired full dignity. The emergence of the concept of informed consent is the subject of the fourth chapter written by Emmanuel Betta. Historical research on this topic has concentrated on the twentieth century, although it has revealed the existence of discussion on the issue already in the eighteenth and nineteenth centuries. Through examination of the *British Medical Journal* and the *Bulletin de l'Académie Nationale de Médecine de Paris* in the years between 1840 and 1900, Betta seeks to establish whether and how those two prestigious medical journals debated the issue of the patient's consent to therapy proposed by the doctor during a period marked by great changes in medicine. Betta shows that the problem was strongly felt within the medical communities of Great Britain and France. He demonstrates that informed consent – by which is meant the patient's expression of a conscious and binding decision on the therapy proposed – arose in the medical sectors of the two countries in the form of a search for the legal safeguarding of doctors in their exercise of a profession which still lacked clear rules. Betta takes a comparative perspective to reconstruct the terms of the debate and its reference to a growing corpus of cases. Patient consent proves to have been a transnational problem which the two countries' medical classes addressed in like manner but with some internal differences. In Britain the debate was explicit and sought to formalize the features of the consent given by the patient. In France, the discussion was less developed, and an argument characterized by medical paternalism prevailed. In both countries, however, the same conclusion was reached: not to grant patients the right to know their medical conditions and to express their opinion on the treatment choices, but rather to protect the doctor against possible indictment. Emmanuel Betta's chapter aids understanding of the dynamics that arose in the doctor/patient relationship at the beginning of the professionalization process. It was at that time that doctors reversed to their advantage the logic of the recovery pacts whose purpose since the Middle Ages had been to protect the patient.

The five chapters that make up the second part of the book are characterized by the fact that they consider medicine, its practices, and its representations not so much in history as in the culture of doctors and patients. In an interdisciplinary dialogue – which is the distinctive feature of the medical humanities – the contributions in this part of the book suggest hypotheses and procedures for management of the patient/doctor relationship so that care encompasses the entire spectrum of the experience of illness. All the chapters conceive culture as a continuous process of construction and co-production of meanings and practices whereby individuals shape and interpret themselves and their world. Within this world, space, time, and the ways in which humans conceptualize and experience the phenomena of disease assume increasingly significant dimensions. The need to consider biomedicine and science as human practices, ongoing processes of reality definition, and constant comparison with other medicines, other paradigms, other conceptions of the body, health, and ultimately of human existence, inevitably requires a multiperspective and multidisciplinary analysis. For this reason, the cultures of care described in this second part of the book are analysed by the various authors in relation to diverse socio-cultural dimensions of medicine and disease: the concept of culture in the anthropological sense of the term; the concrete practices of health professionals; the knowledge conveyed by television representations of medicine; administration of the end of life in the West; the approach to palliative care in such a different social and religious context as that of Saudi Arabia.

The second part begins with a chapter by the anthropologist Ivo Quaranta. It can be considered a preliminary study and a theoretical and practical guide for those, doctors or researchers, who today intend to conduct discussion on illness which covers the many socio-cultural dimensions involved in care relationships. Quaranta reviews and simultaneously deconstructs the works that, from those of Arthur Kleinman until the recent *Report on Culture and Health* of the Lancet Commission, have induced anthropologists and doctors to argue that the doctor/patient relationship should comprise communication which evinces the meanings that patients attach to their suffering. The awareness that sickness is not only a physiological condition of the body but also a cultural and symbolic category entails consideration of biomedicine as one ethnomedicine among others, as a set of culturally and historically determined knowledges and practices. The doctor/patient encounter is thus conceived as a performance in which two different cultural constructions of the clinical reality are enacted. According to Quaranta, investigation into the conceptions of patients is only a provisional stage of the treatment. Quaranta takes a critical stance that spares not even the best practices that have regulated the doctor/patient relationship in recent times: for instance, the idea that in the case of informed consent priority should be given to the autonomy of the decision-making subject. He wonders if good communication with patients is indeed sufficient to protect their interests, especially when their socio-economic circumstances jeopardize their health. As demonstrated by the life-stories of Janice, a Nigerian immigrant in Italy, and of AIDS patients in Cameroon, collected by the Italian anthropologist during his field research, the difficulties that patients encounter in adhering to therapeutic prescriptions often do not depend on their cultural conceptions, but on the precariousness and difficulty of their lives. According to Quaranta, therefore, the challenge faced today by patients and health professionals is not only that of interpreting the meanings of illness and improving communication with each other, but also that of constructing a care pathway that integrates the changes expected from biomedical intervention with changes in the sense relations and social relationships in which patients are involved.

The sixth chapter, written by the gastroenterologist Davide Festi and the dieticians Francesca Pasqui and Carolina Poli, frames its discussion within the everyday practice of the profession, highlighting the difficulties and potentialities of the doctor/patient relationship in the field of functional gastrointestinal diseases. Festi, Poli and Pasqui recount the results of experimental use – at the gastroenterology unit of the Policlinico S. Orsola of Bologna – of the symptoms and food diary for clinical purposes and to improve the doctor/patient relationship. The research by the three doctors started from the premise that the collection of data on the patient's history and understanding of the latter by the doctor does not always come about with the timing and in the manner necessary to create an empathic relationship. They then tested use of the diary as a tool with which to analyse, compare, and relate the different concerns and priorities (strictly clinical for the doctor, eminently existential for the patient) of those involved in the care relationship. The recording by patients of their symptoms and dietary habits – which in gastroenterology has primarily concerned eating disorders – has proved useful not only for obtaining information often omitted during the clinical interview but also in determining the cognitive, emotional and behavioural, as well as dietary, characteristics of the patient. Analysis by Festi, Poli and Pasqui of a sample of 258 diaries – collected since 2010 – led to the twofold conclusion that keeping the diary has positive effects at clinical level and on the doctor/patient relationship. Reiteration of the diary made it possible to identify even severe organic pathologies not apparent during the clinical interview; while the doctor's discussion of the diary with the patient generated fruitful dialogue. Finally, the act of writing the diaries encouraged the patients to conduct more thorough self-analysis of their behaviours and situations of suffering.

The terrain on which Valentina Cappi, in the seventh chapter, tests the doctor/patient relationship is popular culture, of which she provides a twofold definition: popular culture is the culture transmitted by the media and especially television; it is also the social arena in which individuals construct their experiences of illness before or during their treatment by healthcare professionals. Drawing on field research based on interviews and questionnaires carried out with television viewers and health practitioners in central and northern Italy, Cappi shows how individuals internalize and use in their life-worlds what they seen on the television screen. Her research evidences the limitations of studies on the media and health care, which to date have only analysed the representations of medicine furnished by the cinema and television, without investigating how television viewers negotiate and circulate the meanings of illness conveyed by those representations. Cappi instead shows that television medical dramas have influenced the knowledge, expectations, and practices of audiences. They have thus helped to reconfigure the relationship between the supply of, and the demand for, health care and the doctor/patient relationship. According to Cappi, not only have television medical dramas familiarized viewers with specialist medical language and clinical settings which they previously feared or avoided; they have also given viewers a 'media capital', a stock of information, which they use in dealings with their doctors. Comparing the results of this research with those of studies on English and French medical dramas and viewers, Cappi hypothesises that medical dramas influence how people narrate their illnesses. There is thus a circularity between biomedical and popular models beyond national imageries that gives rise to a cross-cultural and transnational reconstruction of knowledge about illness.

The chapter written by Giuliana Gemelli reflects on how, at various times and in diverse places, societies have developed the care-giving dimension. Gemelli reconstructs the growth of hospices as institutions providing end-of-life care. This life-phase of patients is characterized by a multiplicity of aspects to do with the sufferer's personal and social existence: anthropological, cultural, political and religious. Gemelli consequently criticises the reductionism inherent in a Western medical culture increasingly dominated by technology and specialization and increasingly less amenable to listening and dialogue. Gemelli returns to the origins of palliative care. She shows that the hospice is not, nor should it be, merely a hospital; rather, it should treat the person as a whole. This requires health professionals not only to observe and record clinical data but also to possess maieutic skills. After mapping, diachronically and geographically, initiatives and institutions related to care of the severely ill from antiquity until the present day, Gemelli considers the situation in contemporary Italy, of which she describes the features, services and limitations. The hope running through the entire chapter is that hospices will not remain isolated institutions but will become part of a broader philosophical and organizational horizon centred on the *person*, and on society's responsibility for relieving the 'total pain' of those in the terminal phase of their lives.

The result of research conducted in Saudi Arabia, the last chapter written by Omar Bortolazzi addresses in regard to palliative care one of the central themes of medical humanities: the relationship between medicine and religious cultures. He does so in a context, Saudi Arabia, deeply influenced by the Islamic religion. Through the words of the prophet Muhammad, Bortolazzi introduces the reader to a world where, by tradition, the mental and physical suffering caused by illness is seen as a test of faith in God; and where treatment, which is equally in the hands of God, requires an act of faith. The doctor is an instrument of Allah, who allows the use of therapies and medical technologies to improve the quality of the sufferer's life. The doctor and the patient interpret each other's roles within a system of norms, expectations, and ethical values prescribed by Islam. Within this sociocultural frame, Omar Bortolazzi reports research conducted in clinics of Saudi Arabia on the most recent approaches to palliative care in that country. Besides considering the spiritual aspects of such treatment, the author examines other matters: economic factors, medical technologies developed in the late nineteenth and early twentieth centuries, the implications of the use of foreign practitioners in Saudi Arabian hospitals, attitudes towards the use of analgesics and morphine in patients at an advanced stage of disease, and, not least, the diversity of the treatment and responsibilities reserved for women – doctors or patients – by Saudi Arabian culture. These are issues of great current importance which yield more detailed knowledge about approaches to illness and care in a cultural context different from the West but which are still driven by the need and the desire to care for life in all its dimensions.

To conclude, this long-period study on the doctor/patient relationship has brought its historical and cultural dimension to the fore. Given certain structural elements that have defined the relationship since the classical age (for example, medical confidentiality), it has reflected on the changes which have involved the doctor, the patient and society over the centuries. There long coexisted behaviours of opposite kinds in this transformative process. Consequently, univocal notions such as the defensive egoism of doctors or the hostile recalcitrance of patients should be used with caution. The overall picture that emerges from analysis of past ages is instead one of a dynamic relationship in which both parties defended their interests, but which at the same time was characterized by trust in the doctor. In comparison with the past, there emerges the global dimension assumed in the twentieth century by the doctor/patient relationship and the cultural factors that have shaped it. Among these factors are the religious ones that generate differences among medical contexts made uniform by the application of universally endorsed protocols; and the influence of the media, which standardize information and the representation of medicine among their various audiences. The study also highlights that communication and narration, understood as constitutive aspects of care, are the elements which link the past to the present. The everyday clinical practice and sensitivity to pain and the terminally ill that have become part of contemporary culture demonstrate – when compared with the controversial behaviours of doctors in the past – that modern medicine concerns itself not only with cure but also with care.

Notes

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Historical paths

Chapter One

Medicines, doctors, and patients in Greek and Roman society

Daniela Rigato

Investigating the doctor-patient relationship in the ancient world, especially its Greek and Roman areas, requires examination of a system of scientific thought – namely, ancient medicine – which for long shaped subsequent knowledge and reflected a highly composite world.[1] Numerous studies have thoroughly investigated its birth and development across a time-span extending from the thirteenth century BC to the fifth century AD, which corresponded to an equally broad territorial expanse ranging from the Mediterranean countries to the lands of north-eastern Europe.[2]

As is often the case when phenomena of the past are analysed, it is essential to take account of the shortage or partiality of the sources, their heterogeneous nature, and the inherent difficulty of collating the data obtainable from them. The topic of this chapter, in fact, requires information from archaeological, epigraphic, literary, and papyric documentation – this last originating from Egypt, one of the cradles of pre-classical medicine.[3] Moreover, the new information that derives from the progress of knowledge requires inquiries to be constantly updated as opinions change: an example is provided by the autonomy granted in recent decades to Roman with respect to Greek medicine[4] and, as will be specified below, the recent prevalence in the literature of a less contrastive view of different types of medicine, particularly in Ancient Greece.

A plurality of medicines: divine medicine

The foregoing specification introduces one of the most significant and distinctive features of ancient societies. It also concerns the Greek geographical area with its extension in the Mediterranean *koin*è characterized by the co-presence of different types of medicine.

The land that was the cradle of so-called 'rational' medical science – also termed 'naturalist' because of the role of the *physis* in this new medical system[5] comprised at least two other 'medicines' with well-defined and sometimes competing roles.[6] The science of Hippocrates,[7] who founded the rationalist medical thought which developed from the fifth century BC onwards, had to contend with the presence of a 'templar' – or more properly 'divine'[8] medicine – and a 'magical' medicine often the refuge of the ignorant poor and the last resort for the desperately ill. Nor to be overlooked is the body of knowledge stemming from personal experience and tradition, which can be termed 'popular' medicine and is a constitutive part of every human culture.[9]

Given these circumstances, it is logical to expect that in the 'medical market-place' of the Greek world (and the ancient world in general) as described by Nutton,[10] there operated individuals with highly disparate training and who held equally diverse attitudes to the doctor-patient-illness relationship. The picture is further complicated when we consider that the function of the doctor, in the broad sense, was also recognized in divine thaumaturges to whom were attributed miraculous healing powers obtained mainly through *incubation*.[11]

The need to resort to 'divine' doctors can be fully understood by considering the ontological status of disease.[12] For the ancients, illness existed outside the human body, had a specific material form, and could be used by the gods to punish the sins of impiety committed by humans. This conviction is confirmed by various testimonies. A well-known passage of the Iliad, I, 43-67, describes how *loimós*, a common and irreversible disease – a 'collective mortality'[13] – struck the encampment of the Greeks besieging Troy: Apollo, offended by the shameful treatment of his priest, took revenge by visiting a sudden plague upon the Greeks. In a different geographical and chronological context (2nd to 3rd centuries AD), a series of epigraphs in Caria, a region of Asia Minor, resumed the guilt-disease couplet. In this case, the angry deity was Men, a moon god of Indo-Persian origin. Men was responsible for disease but, at the same time, he alone could heal it, provided the faithful recognized their errors, expiated them, and gave thanks to Men by inscribing a stele, a ritual with which to cleanse oneself of sin and the final act of the process.[14] For the *magói* – charlatans who treated diseases with purificatory ceremonies and incantations accompanied by dietary prescriptions and prohibitions, types of behaviour, and the use of baths – epilepsy was the paramount 'sacred' disease. This notion was vehemently contested by the new naturalistic medicine in the Hippocratic treatise on the *Sacred Disease*, which declared that epilepsy had natural causes.[15] For his part, the mild Asclepius warned the faithful whom he healed that if they failed to render the offerings promised in exchange for being cured, he would annul the beneficent effects of his intervention.[16] But this apparent harshness of Asclepius – son of Apollo and the Greek god of medicine – concealed the need of priests and other collateral practicioners to respect the rules that regulated access to, and 'use' of, the *Asklepieia*. In fact, a significant factor in understanding the success of templar medicine was the profitable business of the sanctuaries, especially in the second half of the fifth century BC. These shrines became centres of pilgrimage, especially those with a medical tradition, whose priests and staff with medical knowledge worked actively to increase their range of action and fame.

Asclepius: the divine iatrós and Hippocratic doctor

Together with the centres of worship devoted to other deities attributed with healing powers – Apollo, Hercules, Amphiaraus, Trophonius, Athena, Artemis, Serapis, Isis, numinous figures, and local heroes associated with the healing virtues of water – the templar complexes dedicated to Asclepius (Aesculapius in the Roman world) were the main sites of divine medicine. Widespread throughout the Mediterranean basin, and active between the fifth century BC and the fourth century BC,[17] these temples were the scenes of countless healings, as testified both by inscriptions collected and engraved on large steles erected for didactic and propagandist purposes by the temple priests, such as the *iamata* of Epidaurus,[18] and by anatomical ex-votos depicting the parts of the body healed.[19] Asclepius's impressive actions were recounted by the healed believers to the priests before they left the temple enclosure and successively they were carved onto stone. The god's actions were also described by figurative reliefs[20] or by the plots of comedies[21] which were somewhat irreverent towards Asclepius and his actions: he appeared in a dream to the drowsy patients (*enkóimesis*, *incubatio*)[22] resting in special rooms (ábaton/*enkoimetérion*), and he imitated the gestures of a doctor. Asclepius instantaneously healed by placing his hand on the painful part of the body. Or he was helped by assistants, termed *zakóroi, therapeúontes* in inscriptions, who were often his children and in particular his paredra *Hygieia*, all of whom had curative functions, as also testified by their names.[23] Or he healed with the help of an animal sacred to him (snake, dog, or goose). He bandaged limbs with medicaments, as recalled by Pindar.[24] He performed complex surgical operations, unthinkable for doctors and miraculously painless, during which he extracted spearheads from wounds, worms and leeches from the belly, and put eyeballs back into their sockets. In a particularly astounding case, he healed Arata, a Spartan woman suffering from dropsy, by severing her head and draining large quantities of liquid from her upturned body. He then re-attached the woman's head to her neck. But what makes the operation even more astonishing is that it was accomplished as Arata's mother dreamed of the experience while sleeping in the temple's *incubatio*, while her daughter, who had remained at home, had the same dream, from which she awoke cured.[25]

Scholars have been highly sceptical of these feats, and they largely reject the 'miracles' reported by tradition. But to mitigate their scepticism, in attempting to determine the reality behind these 'critical' cases, they have concluded that many diseases had psychosomatic causes. Some examples follow. Nicanor was lame, and while he was awake a boy snatched his crutch and ran away; but Nicanor stood up and chased him, and thus was cured.[26] While a dumb girl was walking in the sanctuary grounds, she was frightened by a snake sliding down a tree. She screamed to call her parents and regained the power of speech.[27] In these cases, the 'miracle' required neither sleep in the ábaton nor the direct presence of Asclepius, but rather the patient's desire to be cured.

By contrast, in other epigraphs,[28] like those of the Cretan *Asklepieion* of Lebena,[29] Asclepius recommended specific remedies against disease. He specified when and how 'drugs' should be taken and suggested a treatment regime, i.e. culinary rules aimed at preventing and treating disorders of the body. Added to these were prescriptions in regard to physical exercise and bathing, which testify to a perfect alignment of divine medicine with coeval scientific advances in natural medicine; in short, Asclepius worked as if he were a physician with Hippocratic training, and as if he had studied medicine.[30]

These behavioural choices of the priests – devoid of miraculous character and deliberately made by the stewards of the cult of Asclepius – are confirmed by a particular source: the *Sacred Tales* of the orator Aelius Aristides.[31] Unique in the literature, these provide a direct account of the long period of time, almost two full years between 145 and 147 BC, which Aristides spent in direct contact with Asclepius in the great sanctuary of Pergamum. It is evident that Aristides had a complex egocentric personality with a streak of megalomania and marked hypochondria.[32] An 'eternal patient', he furnishes a case study for analysis of the relationship with oracular and healing deities, to which he turned at moments of crisis produced by his illnesses, recognizing Asclepius as the divine *iatrós*. The importance of oneiric experience pervaded his entire existence: through his dreams the deities became an integral part of his life. He claimed that he had recorded all of them by divine will, for Asclepius had commanded him to make their content known. His accounts are replete with dialogues, speeches, visions, prophecies, responses and remedies of every kind – in particular, ones centred on diet and exercise, and therefore in keeping with the trends of contemporary naturalist medicine. As a result of the new theories expressed by Hippocrates and his school, diet occupied, as said, an important place in Greek medicine, which was aware that ingested food and drink influence the body's inner balance, and that an excess or a lack of them might provoke disease. Physical well-being could therefore be restored by altering the diet and taking the correct amount of exercise and bathing.[33]

Asclepius' prescriptions varied in their complexity, and they required the oral administration of solid and liquid preparations based on natural elements, as depicted by a relief of the fourth century BC.[34] Recurrent in them was the use of numerous shrubs and aromatic plants, pepper and resinous wax, as well as ingredients like honey, oil, milk and herbs. These were used in both the prescriptions of pharmacologists and those of popular medicine. Therefore understandable is the 'necessary' presence of doctors at the sanctuaries, where they complemented the role of the priests, often devoid of medical skills, and who were instead responsible for the management of rituals and interpretation of the dreams recounted by the faithful.[35]

Asclepius and doctors

The presence of doctors at the therapeutic sanctuaries is therefore not surprising. Analysis of the documentation, epigraphic in particular,[36] shows the existence of an intense relationship between Asclepius and this category of practitioners. It also confirms the existence of a perfect match between the chronological development of the cult of Asclepius and that of Hippocratic medicine – especially in the second half of the fifth century BC, which marked a crucial turning point for both 'professional' and divine medicine. What emerges is a clear desire to adapt the figure of Asclepius so that it was as similar as possible to that of the doctor, given that they were both specialists in the art of healing. Because medicine had started along a new path which distanced it from the treacherous sphere of magic, it was necessary for the figure of Asclepius to be modelled on that of the doctor. Moreover, with the exclusion of the divine origin of disease, there was no longer reason to oppose Asclepius to natural medicine, which did not eschew the use of sacrifices and consultations through *incubatio*. The doctors, in fact, never disputed Asclepius' therapeutic powers; indeed, they likened their professional role to that of one of his priests – as happened at Kula, in Asia Minor, where a certain Lucius covered both roles.[37] An emblematic case is that of the celebrated Caius Stertinius Xenophon, doctor to the emperors Claudius and Nero, who was also awarded the title of perpetual priest of Asclepius in his home town of Kos, where one of the most important medical schools of the time was located.[38] Indeed, doctors sometimes attributed even the healing of patients to Asclepius, or at least substantial help with their cure.[39] Originating from the Roman province of *Germania superior*, and specifically the town of Obernburg, the site of a fort built on the *limes*, is an altar dedicated to Asclepius and other deities by a military doctor, a native of Ostia. He erected it in gratitude for the divine intervention that had been decisive in the healing of the prefect of the cohort after human action had proved powerless.[40]

Asclepius was honoured by doctors as their ancestor, precursor and the initiator of medical practice, and as the divine protector of medical science. Furthermore, he was believed to be the direct progenitor of the Asclepiades, a family devoted from its origins to worship of the god, which preserved knowledge of the medical art and transmitted it from generation to generation. Of course, further and unequivocal testimony of divine support is provided by another of the most famous physicians of antiquity, Galen, whose treatises of the second century BC evince his faith in Asclepius' curative powers.[41] Galen described the aid furnished by Asclepius in treating severe illnesses with prescriptions received in an incubated dream, and from which Galen himself had benefited as a young man.[42] Moreover, he was thoroughly acquainted with Asclepius' prescriptions and noted how the faithful at Pergamum endeavoured to follow his advice, contrary to what they did with their doctors' instructions, which were often less scrupulously observed.[43] Rather than condemn divine medicine, Galen preferred to present Asclepius as a model because of the trust that he inspired in his devotees.

From a different point of view, it is evident that the sanctuaries of Asclepius were places where doctors could acquire experience, promote their businesses, acquire clients, and compete against one another, thereby increasing their prestige. Testifying to this is the presence in the temple precincts of decrees honouring public doctors worthy of civic recognition, and dedications to the god of the instruments used by the profession.[44] In short, the temples of Asclepius may be considered the first 'public' providers of Western medicine, although it seems that they never assumed an official role in caring for the sick.[45]

The choices of the sick: deities, doctors or both?

In the dialectic between the two types of medicine, it is useful to conduct rapid verification of the choices made by the sick, or at least those of which epigraphic traces remain. A survey conducted on a small, though scrupulously investigated, sample concerns dedications found in microasiatic Greece.[46] Whilst, on the one hand, the survey identifies unilateral choices – only deities or only doctors – on the other it furnishes evidence of a form of complementary action: the sick simultaneously sought the help of both a god and a doctor, whom they combined in their expressions of gratitude for being treated and healed. 'God saved me, and the doctor cured me': these are the words of a devout woman engraved, perhaps between the second and first century BC, on a memorial tablet which states the name of the doctor, a certain *Dionysios*, although a fracture in the stone obliterates the name of the god – perhaps Asclepius – together with the *Tyche* of the city.[47] The same situation recurs in another inscription written on the same stele, and whose conserved portion of text gives the names of the patient, the servant *Lucius*, the doctor *Trophimos*, and the affliction cured – a genital disorder.[48]

These examples therefore seemingly demonstrate that the two forms of medicine were not irreconcilable for the sick, because they received gratitude in equal measure. In these cases, everything was done in order to ensure the best possible chances of recovery.

Turning to cases in which patients opted for one or other of the two types of medicine, an interesting example comes from the Roman province of Syria.[49] A modest altar, erected as an ex-voto in a sanctuary between the second and third century AD, also shows the reason for appeal to divine help. The patient had been treated by thirty-six doctors but they had failed to cure him. He consequently invoked the god, who prescribed the use of a plant. The incompleteness of the text prevents knowledge of the name of the god, probably of local origin; and also unknown is the type of vegetable medicament suggested, which was perhaps castor oil.[50] Although the number of doctors seems symbolic, nonetheless evident from the epigraph is that they were involved before the patient appealed to a god, to whom he turned because of the human inability to cure him. Further testimony is provided by the story of the celebrated tragedian Aeschines: in three months Asclepius cured him of an ulcer on the head which doctors had tried to heal for a year.[51] Aeschines' decision to resort to Asclepius was presumably due to his fear of the painful medical therapy, which consisted of the triad *phàrmakon*, *kaûsis* and *tomé*, i.e. purgatives, cauterization, and surgical incisions, as listed in Plato's

Protagoras (354 A) – and which, moreover, had to be paid for.

Finally, there were patients who appealed directly to a god without seeking the help of a doctor. But as always, the divine intervention came at a price. Besides the costs of transport and accommodation, which increased according to the distance of the sanctuary, there were the expenses of purchasing a sacrificial animal and possibly an ex-voto. However, the burden of the 'divine fee' was off-set by the fact that, unlike the doctors who demanded payment before they would demonstrate a cure's efficacy, Asclepius claimed his due only if the treatment was successful, in accordance with the 'agreement' reached with the believer. In short, the patient's decision seems to have been influenced by a number of factors, but principally the absence in some areas of competent medical practitioners, the low success rate of rational medicine, personal conviction, and last but not least, economic circumstances. What is certain, however, is that if one of the two possible treatments proved unsuccessful, the patient still had a second chance by taking the other treatment.

The figure of the Hippocratic doctor in Greek society

> "The new medicine consisted of secular, rational, and efficacious knowledge concerning bodies and the treatment of diseases ... knowledge which sought to conquer professional space in a field which ... required complex skills and direct and specific experience."[52]

It is thus that Giorgio Cosmacini describes the new Hippocratic medicine; and it is in these terms that one must delineate the main features of the Hippocratic doctor as he exercised his *iatriké téchne*.

In classical Greek society, doctors were considered on a par with artisans, and the Hippocratic treatises referred to medicine as *téchne*, a term which combined the notions of art, competence and manual skill, and also suggested knowledge that was learned and comprised a theoretical part (the 'why') and a practical one (the 'how').[53] Its development therefore caused the progressive secularization and desacralization of illnesses, which were made concrete by the attribution to each disease of a human name.[54] In Plato, a contemporary of Hippocrates, the doctor is portrayed as the representative of a doctrine that was highly specialized and refined in its method, with a professional ethos, and exemplary in regard to the relationship between knowledge and a practical-ethical purpose.[55] This, therefore, was a figure exalted for its social and cultural value, whose effects are apparent in the literary sources, and especially in the medical treatises and encyclopaedias of the imperial age, like those of Celsus and Galen. However, these texts were biased towards an elite of doctors, while, with few exceptions, the ordinary or 'bad' *iatrói* were neglected.

In everyday life between the fifth and fourth centuries BC, the Hippocratic doctor was a practitioner with indistinct features, although he was tied to the *polis*, in which he became a familiar figure and consultant. However, he was primarily an itinerant who moved from place to place to learn and to put his knowledge at the service of those who needed it.[56] The medical art was learned from other doctors because there was no officially organized training system. Moreover, as Vegetti states, there were no hospitals to ensure preparation, and professional competence was not certified by any public authority or medical order.[57] Moreover, instruction in medicine was the monopoly of a few families and handed down from generation to generation. Only with Hippocrates (Coo 460-Larissa 375/351) and his school did the transmission of medical knowledge extend to external disciples who paid to be trained, gradually moving from oral to written instruction. Another characteristic of the classical age was the lack of training in specialized medicine and the consequent absence of specialists.[58]

For the Hellenistic period, account should also be taken of the court physicians, the *iarchiatri*, who were given high rank. Indeed, in some cases they became intimates of the king and his most powerful ministers, and they were also used for tasks other than medical ones. Moreover, the analysis conducted by Marasco shows that none of them were among the founders of the famous medical schools of the Hellenistic age; nor were they the most renowned representatives of that period's science. On the contrary, these doctors appear to have been competent professionals aware of all the technical advances in their discipline and experts in the preparation of medicines of various kinds. The reasons for this specific 'professional profile' are evident if we consider both the duties that the position of court physician involved, and the skills required for the office: continuous attendance on the king, even during journeys and wars; the exercise of constant therapeutic activity in service to the royal family and dignitaries, without time for personal study and research.[59] The selection of archiaters was greatly influenced by the fame of the master from whom they had learned the discipline, the school which they had attended (with preference given to that of Kos and especially of Cnidus), and, of course, their reputation and skill, especially in surgery.[60]

More fruitful for investigation of the relationship between doctor and patient is therefore the figure of the 'city' or public doctor, the *demósios iatrós*: a position universally recognized and rewarded with a guaranteed minimum wage paid under a contract binding the doctor to the city in which he must practise for a certain period of time.[61] Plato (Gorg., 514, de) and Xenophon (Mem., IV, 2.5) provide some information on the selection procedure by the *poleis*: the choice was made by the popular assembly, and the candidate had to pass a test that in Athens took the name of *dokimasía* and which consisted in demonstration of dialectical abilities in a public competition. Moreover, the candidate had to provide evidence of his action and his experience – the patients whom he had healed. Most doctors practised privately and divided their time between work in their surgeries and visits to the sick. It is unclear whether the public doctor was required to provide free treatment to the needy: this may have been the case in the Athens of Pericles; but Jouanna[62] claiming the authenticity of a scholium to Aristophanes, argues that in the classical age all doctors were obliged to give free treatment to those who came to them. What is certain is that there was a system of taxation (*iatrikón*) of wealthy families which enabled even the poorest citizens to use the public service.[63] As regards the problem of the fee (the *misthós*), neither epigraphy nor the technical literature furnish reliable information. Only one Hippocratic treatise (*Precepts*, 69) recommended the doctor to take account of the patient's financial situation, and to furnish free treatment if it was necessary. Indeed, very few inscriptions mention private doctors providing care without payment. Such treatment was reserved for only some citizens or for important personages, such as ambassadors who fell sick during their missions.[64] An exemplary case is that of the slave *Lucius*, cured without payment by Kibyra in 100-200 BC, who thanked both the doctor and Asclepius.[65] A well-known case in the second century BC is that of the doctors heaped with offices and honours who treated their fellow citizens without charging fees.[66] Conversely, there are examples of doctors who accumulated great wealth, like Stertinius Xenophon,[67] and of demands for exorbitant fees – a practice condemned by a motion passed by the council of doctors at the *Mouseion* of Ephesus which denounced the greed of certain doctors and demanded their compliance with ethical obligations.[68] We shall return to this matter below.

The citizen doctor might have paying pupils whom he instructed, and he was helped by assistants, often slaves, who according to Hyginus (*Fabula*, 274.10) were not allowed to practise on their own account. We know how the doctor's surgery (*iatreîon*)[69] was organized from various treatises, and also from Galen – *De medici officina, De decorum, Galeni De methodo medendi* – and iconographic items such as the perfume container known as the Peytel *aryballos*, dated to circa 470 BC, on which is depicted a doctor making an incision for bloodletting while other patients with evident bandages wait to be examined.[70] As Marinozzi emphasises, it was with the institution of the *iatreîon* that the doctor-patient relationship began to be connoted by a ‘place’ that would remain unchanged for centuries. Doctors acquired premises where patients could go to receive treatment.[71] Their dispensaries functioned simultaneously as consulting rooms, pharmacies, and clinics because general practitioners had to treat all diseases and prepare the remedies, in particular purgatives, emetics and laxatives. Here surgery was performed and the operations – incising and cauterizing – most characteristic of the doctor’s work. According to some sources, slaves and the sick of humble social rank were the most frequent users of the surgeries – as described, for example, by a passage in Aeschines’ *Against Timarchus* (123-4).

The doctor also made home visits to patients who could afford private treatment and, if requested, he would travel to other cities. On leaving his surgery, he had to take with him apparatus worthy of his reputation and prestige. Nothing should be left to chance. According to the treatise *Epidemie* (VI, 4.7) he should groom his appearance and attend to his clothes, nails, hair, perfume, and speech.[72] On entering the house, the doctor should be immediately credible to the patient and the family circle, taking care not to arouse contempt or resentment, and he should adopt a demeanour neither too humble nor too arrogant. But it was the doctor’s first inspection of the patient that determined the most important aspect of his credibility, the strictly scientific one – as well described in the second chapter of *Prognostics*.[73] From this first inspection should ensue correct diagnosis and prognosis, this latter being the decisive and conclusive act of the first encounter. Another crucial aspect was deciding what to say to the patient and his or her family after the examination. The situation was exactly the reverse of the one today. In ancient medical ethics, the issue of harming the patient with certain information did not arise; rather, the predominant concern was not to damage the doctor. If the prognosis was grim, it should be pronounced immediately in order to safeguard the doctor against accusations that he had been incompetent or had intentionally caused the death of a patient whom he believed incurable.[74] This the Roman physician Celsus wrote in his treatise *De medicina*, where he counselled caution in treating patients who could not be saved, since that this would also avert the risk of legal prosecution for the harmful outcomes of experiments and innovations made by the doctor. Finally, there was also a protocol concerning the fee, which was agreed before the diagnosis in order to prevent suspicion that the prognosis had been exaggerated to justify an inflated *misthós*, which should instead be proportionate to the economic means of the family.[75] It is also possible that, in small towns, presents and gifts in kind often replaced money – as suggested by the leveret carried by one of the patients depicted on the above-mentioned Peytel *aryballos*. Hence, the doctor had constantly to prove his competence in order to distinguish himself from the numerous charlatans and self-taught healers who competed with him for patients.

The epigraphic documentation, and particularly decrees honouring physicians of the Hellenistic period, convey another feature of the Hippocratic doctor: the obligation to treat the sick without discrimination among them.[76] This is the case of Menophantes, a Macedonian of Hyrcanis (second century BC)[77] who treated all his patients equally; and Damiadas, who practised in the town of Gytheion, where he spared neither zeal nor compassion in caring for all his patients impartially, both the poor and the rich, slaves and freemen. It was for these reasons that, between 73 and 72 BC, the civic community which had summoned Damiadas to Gytheion decided to engrave on a stone exposed in the agora, the heart of the *polis*, a long text which, besides extolling Damiadas' professionalism and exemplary conduct, described how his devotion to the town had been repaid: the granting of proxeny and the title of 'evergete'. Damiadas was also granted the right to acquire a house and land, and he received all the other privileges and honours reserved for proxenes and evergetes.[78] Again in this regard, of great significance is the monument erected to Sarapion – a poet, doctor, Stoic philosopher, and friend of Plutarch – at the beginning of the second century BC, and which has been found in the Asclepieion of Athens. The monument confirms the above assertion concerning the relationship between the medical profession and Asclepius' medicine.[79] It bears an epigraphic ode listing the duties of the doctor and summarizing the principles set out in the Hippocratic Oath, one of the most famous and most widely discussed texts of ancient medicine, and which enables understanding of the composite doctor-patient relationship. The Sarapion poem specifies what should be the doctor's state of mind when treating patients, and how he should behave towards them even if they were of very different social rank: "... in this state of mind, like a wise god, he should take the same attitude towards slaves, paupers, the rich, and kings alike, bestowing his care upon all of them like a brother...."

The ethics of the Hippocratic doctor

The ethical principles just outlined also pertain to the broad topic of the professional ethics of doctors.[80] The first part of the Sarapion poem reads: "These are the duties of the physician: first (…) to heal his spirit and to cure himself[81] before ministering to his neighbour; not to look at or touch (a patient) in a manner contrary to the (divine) laws and the oath. Let his treatment be accompanied by moral qualities and (irreproachable) customs. Let him be reserved when, on giving treatment, he touches young girls or attractive women, and let him forbid his heart to ignite with a passion (unworthy) of a doctor ....”

Immediately apparent is reference to what has been considered the ethical-practical manifesto of Hippocratic medicine: the Hippocratic Oath, the most celebrated text of ancient medicine. Its date is uncertain, between the fifth and fourth century BC; and so too is its attribution: either to the school of Kos or to some philosophical reference environment of Pythagorean derivation, especially in light of certain items like the requirements of purity and the sanctity of life, and the sacred tone that pervades the poem.[82] Its composition correlates with the extension of medicine to practitioners other than the members of Hippocrates’ family, the purpose being to protect the latter’s good name by imposing correct behaviour and consistency of choices on new disciples. Whilst formulation of a genuine medical code of ethics before the fourth century BC was impossible – this being the authoritative opinion of Gourevitch[83] – the Oath can be considered to anticipate a series of basic principles. Some of these are evident in both epigraphic documentation and specific treatises: the definition of fair remuneration, the restriction on medical gesturing, and the prohibition of relationships with patients. Added to these were the gratuitousness of medical instruction; the indissoluble bond between master and pupil and among pupils; the obligation of professional secrecy; and the ban on administering lethal drugs, even if requested by the patient, abortive pessaries, and the excision of gallstones (which caused almost certain death by bleeding or infection). The guiding principle was therefore absolute respect for the patient and his or her interest. The doctor and patient must be united against the disease: this is the meaning of a passage in the treatise *Epidemics* (I, 2) which defines the terms of, and the roles in, the complex relationship among doctor, patient and disease. “The medical art has three factors, the disease, the patient, the physician. The physician is the servant of the art. The patient must cooperate with the physician in combating the disease”. According to what has been called the ‘Hippocratic triangle’,[84] to defeat the disease it was absolutely necessary to obtain the patient’s cooperation. The patient should feel at ease and talk to the doctor, describing experiences indicative of symptoms. The anamnesis thus became an instrument of knowledge used by a method striving for scientific rigour. The Hippocratic method sought to interpret what the senses furnished during observation, and to classify and re-order sensations which, upon correct interpretation, became *semeîon*, or indicative signs.

Once again, the purpose of medicine was to be useful to the patient, or at least not to harm him or her, as stated in *Epidemics*, I, 5 and *Aphorisms*, I, 1; and the doctor had to prevent the suffering of patients and abate the violence of diseases (*De Arte*, 7). To achieve this end, also the patient and the persons around him had to do their duty. Moreover, if the doctor was willing to grant what was pleasing and acceptable to the patient, as suggested by Galen,[85] he would gain greater docility and cooperation with the therapy. This was so notwithstanding awareness of the inadequacy of patients who, ignorant about their ailments, fearful and distressed, would neglect prescriptions, thus risking their lives and the reputation of both the doctor and the *téchne*, and who would sometimes resort to therapies not endorsed by medical science.[86] A special case was the relationship with women, who had more expert knowledge of their bodies and the symptoms of disease, factors which made them more helpful in establishing the case history. Yet this 'positive' attitude was often thwarted by the use of vaginal applications considered dangerous, and for which the physician had to disclaim responsibility. In defence of 'negligent' patients, however, it should be borne in mind that the literary evidence furnishes only a partial account of the reality of the doctor-patient relationship, and that the point of observation on behaviour is almost always that of the doctor-writer. Rare, in fact, are reports of recriminations by patients for alleged faults or failures by doctors, who for their part had no interest in disclosing the number of patients whose deaths they had caused. Unlike the literary texts, however, in some cases epigraphs explicitly state the doctor's responsibility for a death – as does, for example, the epitaph of a child killed by a surgeon[87] Two *tabellae defixionum* may instead have had other reasons for cursing fully seventeen doctors,[88] and also Artemidorus, a doctor of the third praetorian cohort, although his medical skills were not disputed.[89]

The nature of the epigraphic documentation also prevents retrieval of information concerning competition, emulation, conflicts, expulsions, or disqualifications.[90] We must therefore presume the existence of a self-regulation system under the moral authority of some members of the medical 'community', and which operated especially through the sanctions of patients. It was precisely failure and the loss of prestige, and no longer the wrath of the gods, that was the worst punishment for perjury suffered by a doctor in breach of the Oath. Divine punishment had by now given way to a moral sanction harsher and more relentless than any sacred punishment. But aside from routine conduct, the decrees issued in honour of doctors demonstrate that a number of them were able to abide by the Oath. The texts of these decrees emphasise – in vague yet significant language – that the doctors honoured had acted honestly in exercise of their art and in their lives.[91]

Besides professional ability, the ancient doctor was generally chosen for his human qualities. The Hellenistic decrees honoured doctors beyond reproach in regard to *téchne* and personal behaviour, and the Roman inscriptions also insisted on gentlemanly qualities – as seen above in the case of Sarapion. Because the good doctor should therefore be respectable as well as cultivated, medical ethics extended beyond mere technical prescriptions. There are very few epitaphs which do not contain at least one laudatory adjective, even if it is a generic one like *esthlós* (generous, noble, honest, loyal); and the qualities of honesty or gentlemanliness were valued in doctors, who in many cases were described as *agathós*, or *kalós* and *kalós kagathós*. Hence professional and human qualities were bound up with each other. Many inscriptions at Delphi emphasise the compassion of doctors, and the majority of decrees praise their behaviour as model citizens who did not disrupt the public order.[92] Do no harm' was one of the principles of Phanostratè, an obstetrician and doctor of Athens in the fourth century BC, given that his epitaph states that he caused pain to no-one, and that all had mourned his death.[93] The tombstone of Charòn, a doctor in the fifth century BC, declares that none spoke ill of him, not even after his death, for he had relieved so many people from suffering.[94]

As regards city life, to be emphasised is that from the Hellenistic age onwards and especially during the Roman period, doctors – who were usually free citizens – enjoyed substantial exemptions from charges or taxes, financial benefits, privileges; and the doctors of alien origin received citizenship. Added to this was the honour of having one's personal merits mentioned during the official eulogy pronounced before the popular assembly on the occasion of important events, or the *Asklepieia*, the festivities held in honour of the doctors' divine protector. Also in the case of private doctors who had shown devotion and competence in their work, there are testimonies of homage paid to them by the community. Sometimes, the honour consisted in bestowal of a crown, often made of foliage, which was intended to encourage the physician to continue in his work so beneficial to the city, while a gold crown was reward for care exceptional in its duration or quality. A city might also erect a statue to a doctor: examples are Satyros, who received, besides the crown, a bronze simulacrum; or Glaucias of Mesembria, who was honoured with a portrait painted on a shield. However, the bestowal of such honours ceased with the beginning of the Roman period, and thereafter the honorific decrees consisted only in enumeration of titles and offices engraved on the base of the statue with mention of the reason for the homage rendered to the doctor.[95]

The Roman world

Medicus Multum celer atque fidelis ... these were the prerogatives required of the doctor according to Horace (Sat., 2,3,147) in a society moving very slowly towards recognition of the professional value of the medical practitioner after a long and tortuous process that had begun around two centuries before. According to the tradition, the arrival in Rome of the first doctor from Greece occurred at two different times: either 219 BC with the Lacedaemonian Archagatos or, according to Dionysius of Halicarnassus (10,53,1), in 303 BC. What is certain is that Plautus' *Menechmes*, composed prior to 215 BC, contains the first instance of the term *medicus*, with a possible allusion to the arrival of *Archagathos*, although he soon earned himself notoriety as a *carnifex*.[96]

The encounter with Greek medicine in Rome, in fact, provoked an anti-Hellenic prejudice whose main exponent was Cato the Elder, a supporter of the *prisci mores* to which the Romans – as Plutarch recounts (*Cato Maior*, 19.4) – erected a statue in the temple of Salus proclaiming an Italic form of medical care to which Rome long remained attached. To alleviate the body's suffering it was much better to use bland medicaments, herbs known to the *pater familias*, and bathing – a practice of which the Romans were particularly fond.[97] The tenacious Cato, wrote Pliny (*Nat. Hist.*, 29.4-6), prevented his son from having any contact with Greek doctors, persons whom he deemed wicked, as practising medicine only for profit, and sent to Roman territory in order to exterminate the barbarians. He censured Greek *téchne iatriké* for the senselessness of its prescriptions and the violence of certain operations, such as bloodletting and cautery, besides criticising the immorality of the physicians who performed them.

Amid this first hostile reaction to one of the Greek *artes*, mention should be made of two episodes involving the Hellenic religious sphere: as early as 431 BC the cult of Apollo *medicus* was introduced in Rome during a plague epidemic; and in 293 BC the cult of Asclepius[98] was imported from Epidaurus into the *Urbs* and officially installed on the Tiber Island[99] in an attempt to stem *dira lues* – a ferocious disease against which traditional medicines were powerless, and which no indigenous god was able to halt.[100]

However, although medicine in Rome became established later and depended on stimuli from the Greek world, already present was a popular medicine with characteristics that differed among the various Italic peoples, and in which magic played a prominent role – especially among the rural population. An example is provided, from the point of view of *medéri* (treatment), by Cato's *De agriculture*, in which spells are associated with legal advice and recommendations for veterinary and general medicine. A sprain could be alleviated by reciting an incantation while binding the limb with reeds, assuming that the healer's power was magically transferred from the reeds to the patient. Cato also dwelt on the therapeutic qualities of vegetables, with recipes that mixed empirical knowledge with magico-religious rituals (particularly recommended were cabbage, because of its digestive properties, and wine) accompanied by various herb-based medicinal potions prepared with specific and almost ritual procedures.[101]

It is thus apparent that in Roman society healing was still a threefold process: the 'learned' Greek component never entirely replaced the Italic expertise consisting in herbalist skills, folk knowledge, and curative practices often bordering on magic and reflected in the *Natural History* by Pliny, who was also resistant to *graecus mos*. Moreover, also the Romans believed that disease was caused by wickedness: both personal suffering and that of the entire population was attributed to hostility against the gods. When a disease became an epidemic, it was regarded as a *prodigium*: that is, a premonition of divine wrath like other terrifying and destructive phenomena – lightning bolts, eruptions, floods, droughts, and famines – a result of breach of the *pax deorum* without which there could be no prosperity. To re-establish the peace, it was necessary to regain the gods' benevolence by means of particular rites.[102]

The doctor in Roman society

The main sources of the doctors recruited in Rome were war and immigration.[103] To be emphasised is the large amount of slaves among them. They can be divided into two groups. One comprised slaves who had been doctors in their homelands and were then transported to Italy as prisoners of war. They can be termed 'doctor-slaves', and their recruitment terminated towards the end of the first century BC.[104] The other group consisted of slave-doctors, who were slaves acquired without medical knowledge or *vernae* and instructed for the purpose of profit. Between the late first century BC and the early first century AD, however, the situation changed: a number of doctors were rewarded for their excellence. Already in 46 BC Caesar had granted such doctors citizenship, trying to tie them to the territory where they worked,[105] and Augustus excluded doctors from the ordinance that expelled foreigners from Rome after the famine of 6 AD.[106] To be noted in this regard is that Augustus himself had his life saved by a doctor: Antonius Musa, a freedman – like the many other slaves liberated for their professionalism – to whom he dedicated a statue.[107] The diffidence of some members of the Roman elite persisted, however. It was due to their suspicion that a profession without clear rules was careless and improvised,[108] as highlighted by Juvenal's satire *contra medicos* (*Sat.*, 3.74 to 78) written between the late first and early second century BC. This attitude may be partly explained by the fact that Roman doctors long continued to be of Greek tradition, so that they spoke and wrote in Greek.[109] But this was not snobbishness; rather, it was the use of technical language to denote concepts, diseases, remedies, and instruments that did not have specific names in Latin. But increasing Hellenization and the expansion of the empire led to improvement in the doctor's image, which in Rome was often directly linked to the biographies of emperors or wealthy landowners. During the first imperial age, in fact, doctors – like philosophers, rhetoricians and philologists – enjoyed special legal exemptions, immunities and privileges which could be strong inducements to pursue a medical career.[110] For practitioners living in outlying areas and the provinces, especially the Eastern ones, the situation was different: they were unlikely to receive the above-mentioned privileges, and there long continued the exercise of itinerant practice – as shown by the epitaph of an anonymous doctor originally from Nicaea who died in Thessaly.[111] Moreover, on the one hand enlargement of the Roman *limes* made it necessary to organize medical care for soldiers, with the consequent creation of the military doctor; on the other, it gave members of the privileged social classes a chance to see new countries and extend the boundaries of scientific knowledge to encompass contexts, customs and substances previously difficult for doctors to access – as in the case of the celebrated Dioscorides,[112] a travelling doctor expert in herbs.

According to Cicero (*de off.*, I, 151), medicine was an honourable career, like architecture, but only for the persons for whom it was suitable – by whom Cicero meant slaves and freedmen. Medicine would therefore be dishonest for a free citizen; indeed, the epigraphic documentation confirms the rarity of its choice as a profession by free citizens.[113] It is obvious that exercise of the profession did not prevent certain personages from accomplishing prestigious careers.[114]

As for the medical category,[115] the profession soon adopted the Egyptian system, which comprised diverse specializations. Thus in the first phase of the empire, also in Rome a distinction was drawn between physicians and surgeons, to be then followed by the multiplication of doctors specialized in particular organs, diseases, therapies and schools of thought with a consequent proliferation of 'sects'.[116] A representative case is that of a doctor practising in Assisi, *P. Decimius Eros Merula*, who described himself in an epigraph as a *medicus clinicus chirurgicus ocularius*.[117] But the over-specialization of Roman medicine was often criticized. Marcus Valerius Martialis (10,56,3-8) derided specialists; and yet he complained that it was impossible to find someone able to treat exhaustion. Galen denounced the excessive and ridiculous fragmentation of medical practice confirmed by epigraphic documentation in Rome.[118]

There are reports of upstart doctors – reflecting everyday reality and the atmosphere in the capital – like Thessalus of Tralles at the time of Nero, who on leaving home was accompanied by a retinue larger than that of a famous actor; or those doctors, stigmatized by Galen, who were able to convince people of their high professionalism through the richness of their garments and rings, the size of their retinues, and the preciousness of their silver tableware. Again, the scornful rhetorician *Lucianus*, who sojourned in Rome between 150 and 164 AD, mocked the ignorant doctors who, although equipped with valuable instruments, did not know how to use them.[119] Doctors were even accused of being 'poisoners' in judicial oratory and the writings of Pliny, who rebuked their lack of scruples, their application of therapies without scientific bases, and also their greed.[120]

Also in Rome, doctors possessed a 'studio', the so-called *taberna medica*,[121] or visited patients in their homes to furnish their services (upon payment). Their clients were mainly wealthy persons, functionaries and, in Rome, all those who gravitated around the imperial court. However, there is no documentation on the relationship with the lower classes, although it is likely that the paupers of the outlying districts and the countryside treated themselves with traditional medicine or resorted to quacks, at least until the belated establishment in the major cities of a municipal doctor, especially in the event of epidemics.[122] The urban medical service was created only by a *constitutio* which Valentinian and Valens promulgated in 368 AD. They did so for both moral and political reasons. On the one hand, help given to needy families prevented infanticide and abated epidemics; on the other, reducing the mortality rate made it possible to maintain a reserve of men to serve in the army, as well as to prevent social unrest.[123]

Distinctive of Roman society was the presence of community doctors. Some practitioners worked at institutions, communities or for professional corporations: they did so, for example, on the occasion of games for athletes or gladiators during contests; for the circus factions,[124] for the staff of libraries and public gardens, or for workers at the harbour of Ostia.[125] But better understanding of the everyday workings of the health system can be gained from examples of abandonment of the profession. Recorded by literary documentation, not without a touch of sarcasm, these examples reflect the Roman society of the first century AD. One reads thus in the Palatine

Anthology: “Diaulus was a surgeon; he has become a gravedigger.” And again: “Once a doctor, Diaulus is now a sexton; he who is now a sexton used to be a doctor.”[126] Evidently, the uncertainty of everyday life and the differences in clientele and earnings among the various categories of doctors induced some of them in straitened circumstances to take up a more lucrative occupation. Nevertheless, there are examples of honours bestowed upon doctors by their fellow-citizens or by municipalities through decrees; elevation to the title of *sexvir augustalis*, the highest honorary office attainable by freedmen; and privileges in wills (although on occasion there was some suspicion concerning the patient’s death).[127]

Another specificity of Roman medicine with respect to its Greek precedents was exaltation of the *pharmacopoeia*, of which only careful management could enable the doctor to assist the sick. Given that medicine was a *scientia sanandi, non nocendi*,[128] its representatives should be aware of the crucial role played by drugs in therapy. Described by the doctor of the Alexandrian school, Herophilus, as the fingers of the gods, and therefore as divine gifts, drugs had necessarily to be used in medical treatment; otherwise, the doctor might be accused of negligence or even a crime if he deliberately refrained from administering them.[129] These statements refer to the thought and work of two important exponents of Roman medicine in the imperial age who were almost contemporaries: Celsus, author of eight books on medicine documenting the health situation in Rome during the first century AD, and Scribonius Largus, physician to Emperor Claudius and author of the treatise *Compositiones*. It would in fact be wrong to assume that the literature rejected the resources of folk medicine, whose ‘remedies’ drawn from peasant culture were fully part of Roman pharmacology. This observation is even more apposite when one considers the conditions in which the itinerant doctors worked. In the absence of more complex drugs, they were often forced to use the resources offered by nature.[130] According to Scribonius, medical ethics imposed a moral duty on the doctor to make his pharmacological skill available to everyone, friend and foe alike.

This is a topic of particular relevance to the present discussion, for it takes us to the preface of *Compositiones*, in which Scribonius propounds, with respect to the Hippocratic formulation, a new medical code of ethics enriched with concepts deriving from the Stoic doctrine of *misericordia* and *humanitas*.[131]

The doctor-patient relationship and the amicus medicus

Of similar opinion was Celsus, who in the *Proemium* (I, 74) of his treatise *De*

Medicina, declared: *par cum scientia sit, utiliorem tamen medicum esse amicum quam extraneum* ("skills remaining equal, more useful is a doctor who is a friend rather than a stranger"). This statement was the result of an evolution in Roman *societas*, from the first imperial age onwards, in doctor-patient relations whereby the principle of compassion for the sufferer became most salient and valued. This meant rejection of all forms of cruelty and acquisition of the threshold limits which scientific research should accept in order not to cause harm: it was now humanity towards the patient that took priority. Celsus (*De Medicina*, *proemio*, I, 66) also declared that the patient must have precedence over the theory and the rules, so that it was essential for the doctor to know the patient's case history, and thereby establish a personal relationship with him or her.

This new orientation also gave rise to social changes entailing a type of professionalism which did not give priority to financial gain – with a throng of patients treated simultaneously – and which drew on an ethical principle already present, as said, in Hippocrates' *Precepts* which recommended that doctors limit their greed for gain and treat paupers and foreigners for free. Part of this new 'philosophy' was a novel conception of pain as a problem which the doctor could not ignore. However, he should adjust his 'compassion' to the patient's compliance with the therapy and curb his or her opposition to prescriptions which, although painful, were necessary for the cure.

Scribonius's concern (*Medicine*, V, 26.1) was therefore to define an ethics of the medical profession while being well aware that the doctor's role (free from state control) could easily fall into disrepute, both because of the risk of fraud or manipulation by quacks, and because of the harmful effects of careless prescriptions or surgery unnecessary to the point of therapeutic obstinacy.[132]

The case of incurable diseases was different. If a patient died, the Greek doctor might lose prestige and clients, and he risked social blame. But the legal situation was considerably different in the Roman world and required a much greater caution. In fact, in the event of a patient's death, the doctor's responsibilities were regulated since the Republican period by the *lex Aquilia*, which sanctioned the *damnum iniuria datum*. In particular, the law punished anyone administering a harmful medicine by force or persuasion, errors committed in surgery, and of abandonment of therapy after an operation.[133] But, as evidenced by Marasco's recent study, "The attitude of the Roman doctors appears far removed from the generalized refusal to treat desperate cases that we tend to attribute to them. On the contrary, there was considerable disagreement within the medical profession on the behaviour to adopt, and numerous doctors were willing to try anything, despite the danger to their reputation and the possible severe legal consequences".[134] In incurable cases, one may anyway presume that the doctor attended closely to the patient to relieve the pain and psychological consequences of the disease.

This conduct brings us to the ideal of the *medicus amicus*[135], which did not differ greatly from the humanitarianism shown by Seneca when he urged doctors to give care to all those who required it regardless of wealth and social rank, similarly what would be expected of a clement emperor or anyone with a position of superiority in social relations: self-control, moderation, generosity and compassion. The medical ethics of the imperial age therefore proposed a transformation of the disease-patient-doctor triad: no longer the Hippocratic triangle but the doctor-patient relation, with interest shifting from the disease as a free-standing objective reality to the care to be given to the patient as an individual. This consideration of the patient as an individual also explains the concomitant growth of an 'ideology' of health: a widespread concern among the affluent classes with self-care and being healthy, which contributed to recovery of the principles of ancient Roman medicine and stigmatized the trend towards ever greater medical specialization.[136]

The new conception of the doctor-patient relationship found complete expression in Galen's writings, where he stressed the extreme importance of the doctor's behaviour and the relationship that he should establish with the patient in order to gain his or her trust: not only acts of kindness but also valid therapeutic choices based on a strategy intended to secure the patient's cooperation. The ideal type of doctor that Galen had in mind required not only disinterestedness and a lack of greed but also a sober and severe lifestyle and a certain degree of education, with expertise in the three main branches of philosophy: logic, physics and ethics.[137]

Investigation should also be made of the diversified relationship between women and the medical profession, and between women and *phármaka*, which this article has only briefly addressed. As Gazzaniga puts it,[138] the world of female medical knowledge consisted of only marginal and evanescent figures. They possessed empirical knowledge which mingled with magic and folk traditions. Endowed with ordinary skills, they were able to deal with minor medical emergencies within the *oikos* and the *domus*. But there were also the women *medicae* (as well as *maiae* and *obstetrices*) recorded by the epigraphic documentation, and who gainsay, at least in part, a *topos* widespread in the ancient world and expressed by the poet Ausonius in a passage where he recalls his maternal aunt as devoted to, and expert in, the medical arts as a man: if she had only been able to act like the 'stronger sex', she would have enjoyed credibility.[139]

However, it would be beyond the scope of this chapter to analyse relations between medicine and the Christian faith, and the role of the new religion in transferring new ideas about treatment of the sick and suffering into medical practice. Christ, Cosmas, Damian, and many others, are actors in another 'story' which led to the creation of the first hospitals and the birth of the hospital system.

Notes

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5 Cécile Nissen, *Entre Asclépios et Hippocrate, Étude des cultes guérisseurs et des médecins en Carie*, (Liège: Centre International d'Étude de la Religion Grecque Antique, 2009), *Kernos*, *Supplément* 22, 58-9.

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8 Nissen, 2009, 58.

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20 *Ibid.*, 33-34.

21 Aristoph., *Pluto*, 663.

22 Pierre Sineux, 'Dormir, rêver, montrer. Les représentations figurées du rite de l'incubation dans les sanctuaires grecs', *Kentron*, 23, 2007, 11-29.

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87 Samama, 2003, nr. 309.

88 *Ibid.*, nr. 494; 506.

89 *Ibid.*, nr. 480.

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122 See *CIL* XI, 3007.

123 André, 1987, 110-116.

124 *CIL* VI, 33879.

125 André, 1987, 108-110.

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un'indagine preliminare, in Alfredo Buonopane, Francesca Cenerini (eds), *Donna e lavoro nella documentazione epigrafica* (Faenza: F.lli Lega, 2003), 113-130 (with complete references list concerning the topic).

Chapter Two

Two actors in the mediaeval therapeutic relation

Tommaso Duranti

In recent decades, also historians of the Middle Ages have shown increasing interest in the doctor-patient relationship. Whereas in 1996 Luis García Ballester emphasised the relative paucity of research directly concerned with this topic, since then a number of important studies have been conducted on mediaeval medical ethics, also from a diachronic point of view, and some of them are very recent.[1] The greater interest in the relationship between doctor and patient, although it was already present in the definition of the so-called Hippocratic triangle (doctor-patient-disease), results from the close attention paid to the not solely clinical value of this relationship by current medical science (concerned to emphasise the importance, ethical but also curative, of a relationship that does not reduce the patient to an object of care, but subjectivises him or her), as well as by medical anthropology (concerned to emphasise the importance of the patient's perception and narration in relating not only to the carer but also to the care).

Seeking not to lapse into anachronism, also historians of medicine have increasingly stressed the importance of analysing this relationship, not as a mere antecedent to current reflection but to gain better understanding of the mechanisms – therapeutic, ethical and cultural – underlying the care relationship in the Middle Ages. A sick person becomes a patient only when he or she relates to a carer. It is therefore rather intuitive that his or her role in that relationship is of central importance when one seeks to reconstruct its coordinates. Privileged attention to the development of medicine as *ars* and *scientia*, the types of sources on which to draw, and the diagnostic and therapeutic limitations of the time, have helped consolidate the stereotype of the doctor of the past as almost 'disconnected' from the patient, sometimes the object of care that was also physically distant, and sometimes the subject of speculation rather than care. If considerations of this kind are not be dismissed, they must be partially qualified. Analysis of the writings of mediaeval doctors, especially from the twelfth or thirteenth century onwards, has shown that even at that time the problem of the relationship with the patient sprang from moral and therapeutic concerns, and that its purpose was not solely to maintain or consolidate professional dignity, with the consequent earnings. Driven by the 'scientific' need to objectify the diseased body so as to render it a locus of care and a source of medical discourse, the mediaeval doctors also perceived the 'moral' (but, as we shall see, therapeutic as well) need to 're-subjectivise' that body: in short, to bear in mind the patient's nature as both an object and a subject. This stemmed from their increasing knowledge of the ancient texts of the Hippocratic-Galenic tradition, which had already addressed the issue of the relationship with the patient, but it also derived from a substrate, not necessarily fully perceived, created by Christianity, whose moral and cultural precepts were part of the training of mediaeval doctors.

The interpretation of disease seems to have been particularly influenced by Christian thought. Consequently, also the sick person, and then the patient, seemingly responded to a system of thought with primarily moral value and soteriological purposes. Etymologically, *patiens* means 'one who suffers', and in the case of illness he or she was subject to mainly physical suffering (which in some cases was deemed to result from a state of sinfulness). By virtue of *imitatio Christi*, who was the sufferer *par excellence*, the patient therefore had to accept the disease with patience. Aside from the extent to which this view really flowed from the reflections of theologians into real life, also the therapeutic relationship seemed to depend on these premises. In early mediaeval Christian thought, especially, the condition of the patient was not manifestly distinct, not even lexically, from that of a sufferer: in short, illness was one of the afflictions that struck the *pauper-infirmus*, who was not only materially poor but also a sufferer. The *pauper-infirmus* was in an ambiguous state of both suffering/punishment and suffering/purification. As such, he or she was seemingly the ideal object of Christian attention in the form of 'indiscriminate charity.' In this cultural context, therefore, the sick person did not 'become a patient.' The relationship that arose between the giver of assistance (which might include forms of care) and the recipient was based on the principles of *charitas* – whose main goal was salvation – and not, or at least not principally, on those typical of a carer/caree relationship instead centred on health.[2] But doctors continued to practice their art, and the sick continued to ask doctors to cure them. Even in the early Middle Ages, of course, there was a relationship between doctor and patient, and above all – despite the lesser availability and the different nature of the sources, as well as less intellectual concern among doctors with ecclesiastical doctrine – there was reflection on the doctor-patient relationship. Subject to such reflection – the result of a cultural context different from the contemporary one – were matters such as safeguarding the doctor's *dignitas*, or the awkward question of fees, which today would be disregarded but in the Middle Ages were considered in every respect components of that relationship. The rediscovery of the so-called 'new Galen' (as well as other authors like Avicenna), and the establishment of medical studies at universities then marked a change of direction[3] in which the patient became more central to reflection on the doctor-patient relationship – albeit still in the classical tradition and that of late antiquity – especially in the subsequent deontological works of the Hippocratic corpus with Galen's commentary.[4]

Ethics and etiquette: the portrait of the ideal doctor

Because doctors are the recipients (not always the authors, especially in the early Middle Ages) of texts that deal with the doctor-patient relationship, considerations on the relationship with the patient usually start from a moral portrait of the doctor. These aspects are present mainly in the early mediaeval texts. The instructions furnished did not constitute an ethical-professional code; rather, they delineated a generic moral portrait in which prescriptions of good sense and 'humanity' alternated with instructions drawn directly from, or indirectly inspired by, ancient and Christian texts.[5]

The qualities required of the good doctor constituted a somewhat stereotypical image centred on the moral status of the doctor as both an individual and a practitioner. It should be pointed out[6] that, with respect to ancient medicine, the early mediaeval texts did not dwell on the virtues that doctors should develop in the course of their training and work; instead, they emphasised a moral system that should be inherent to an individual about to become a doctor. This was due to the influence of Christianity on medical thought; not coincidentally, the early mediaeval texts which dealt with these issues (and which have come down to us) were all produced in monastic settings. It should be noted, however, that the authors took a largely secular approach to the matter.[7] This attention to personal virtues is unsurprising, for a moral portrait consonant with Christianity-inspired norms, but also tied to ethical and political considerations, was present throughout the Middle Ages: for example, it was among the requirements for the various *officia* (also temporal), for public functions, and for admission to graduation examinations, and so on.

It should also be pointed out that, from the thirteenth century onwards, this type of portrait gradually lost centrality in the texts of scholastic medicine. Although it was still mentioned, attention to the qualities required of the doctor was directed more to the technical and psychological skills that the practitioner must learn in order to perform his role satisfactorily. This resulted from better knowledge of the ancient texts and from the different type of works that dealt with these themes: in the late Middle Ages, in fact, it was mainly university doctors who conducted ethical reflection on the medical profession; reflection which was necessarily more detailed and professionally oriented than that of the early mediaeval monastics.

The portrait of the virtues of the perfect doctor was inspired by an ideal of *medietas*. By way of example, there follows the well-known text of a brief ninth-century treatise in epistolary form which summarizes the typical virtues of the doctor in the early Middle Ages:

> what sort of person a physician ought to be. First, he should test his personality to see that he is of a gracious and innately good character, apt and inclined to learn, sober and modest; a good conversationalist, charming, conscientious, intelligent, vigilant and affable, in all detailed affairs adept and skillful. Our art also requires that one be amiable, humble, and benevolent. Humility ever seeks knowledge, ever accumulates, and never goes to excess or offends. Good will restores sweetness, inspires sagacity, maintains remembrances in the heart, love in the soul, discipline in obeying, wisdom imbued with fear and diligence, and respect, for he who loves not honors and will not be skillful or sure in his work. Not be hesitant or timid, turbulent or proud, scornful or lascivious, or garrulous, a publican, or a woman-lover; but rather full of counsel, learned, and chaste. He should not be drunken or lewd, fraudulent, vulgar, criminal or disgraceful; it is not right for a physician to be taken in a fault or to blush for shame in the presence of his people. …. Inasmuch as the physicians has high honors he should not have faults, but instead discretion, taciturnity, patience, tranquility, and refinement; not greed but more of restraint and subtlety, rationality, diligence, and dignity. One of the virtues of this art is zeal in acquisition of wisdom, long sufferance, and mildness. (The physician should strive for) a cheerful pleasant approach; for even as light illuminates a home and makes men see in dark shadows, so a cheerful physicians turns sorrow and sadness into joy, and comforts all of the members of his patient, and restores his spirits ….[8]

These are traditional recommendations that recur in all the coeval texts and also in the injunctions of theologians and moralists (and, conversely, in the criticisms of polemicists and the satirical portraits commonplace in the literature).

Besides these virtues, the texts also made recommendations concerning etiquette – namely the behaviour expected of a doctor both in general and in exercise of his profession – and therefore in regard to the patient, his or her family members, and, later, the doctor's colleagues.[9] Also these prescriptions kept the classical tradition alive. They were inspired by rules of common sense and good behaviour which regulated the doctor-patient relationship – especially in the early Middle Ages – as one spontaneous in its nature.[10] These rules mainly concerned the doctor's appearance, and they derived largely from Galen's commentary on Hippocratic *Epidemics*:

> he ought to hold his head humbly and evenly; his hair should not to be too much smoothed down, nor his beard curled like that of a degenerate youth. He should not use ointment to excess in his hands or the tips of his fingers. He should wear white, or nearly white, garments. He should be lightly clad, and walk evenly without disturbance and not too slowly.

The purpose of these instructions was to ensure that the doctor's appearance emphasised the dignity of his role and his possession of what today would be called a professional (and therefore reassuring) demeanour: "Gravity signifies breadth of experience."[11] This was an attitude, together with certain diagnostic and therapeutic gestures, which had effects on the patient that were comparable, as noted by Michael McVaugh, to those produced today by a white coat or diplomas hanging on the wall.[12]

From the tenth century onwards, there also appeared the first explicit references to the behaviour required of doctor when examining patient. Thus delineated were the first features of an 'ethical' code which combined requirements to do with the practitioner's expression of dignity, and in some cases superiority, with a concern for the patient's interests and well-being.

Whilst in the more ancient texts the question of the doctor's behaviour was addressed only in passing, it was after the works produced by the *Schola Salernitana* that authors dwelled on it to a greater extent. This was due both to the greater availability of ancient writings (also through the mediation of Arabic authors who had already reflected on the matter) and the role of the Salerno doctors, who were both medical practitioners and teachers. Hence the indications arising from classical medical thought had counterparts in practice and experience; above all, they were imparted by the master to his students when new generations of practitioners received their training.

Also in this case, the instructions drew on *topoi* in the medical literature. When examining a patient, the doctor must avoid an ambiguous attitude towards the women of his or her family (indeed, the Visigothic code forbade doctors, except in emergencies, from performing a phlebotomy on a woman in the absence of a family member).[13] He must be modest and affable,[14] have a serene expression on his face (as a consequence of his expertise), dress in rich but sombre clothing, and so on: traits which, it has been noted, were "morally irrelevant, but socially significant and rhetorically efficacious in acquiring esteem and repute"[15] and intended to gain the patient's trust (see below).

In the years between the late thirteenth and early fourteenth centuries, the rise of scholastic medicine in the European universities and the circulation of the so-called 'new Galen' induced more profound reflection on the doctor-patient relationship. Thus inaugurated was a line of inquiry that would engender a professional code of ethics in the stricter sense. With the university doctors, the 'spontaneous' relationship characteristic of the early Middle Ages became a technical one incorporated into an intellectual system based on a distinction among *res naturales*, *res non naturales, res contra naturam*. To these was added the category *res extraneae*: this comprised issues extraneous to disease which were treated by, for example, Arnald of Vilanova and Henri de Mondeville.[16] The texts of the doctors of medicine partly went beyond the traditional ones that had persisted at least until the first half of the thirteenth century (for example, what Guido of Arezzo, a master of logic of the late twelfth and early thirteenth century, wrote in *Liber mitis* slavishly reproduced the doctor descriptions of late antiquity and the early Middle Ages).[17] According to the new generation of intellectuals, the virtues that the physician must possess ranged from moral to more specifically professional ones: primarily, in the words of Arnald of Vilanova, *honestas* and *diligentia*: that is, persistent application in study and practice, competence, and professionalism.[18] There were also references to the ancient moral portrait of the doctor (in 1340, the surgeon Guy de Chauliac resumed the tradition of late antiquity by writing that a doctor should be *morigeratus, graciosus, castus, sobrius, pius et misericors*).[19] But increasingly apparent was a specific concern with professional ethics; a concern which, as said, centred on both the dignity of the practitioner and the interest of the patient. In that period there once again arose the dichotomy of ancient origin between 'what kind of person a doctor should be' and 'how a professional should behave':[20] a development which tended to replace individual morality with professional ethics and which culminated in Peter of

Abano's *Conciliator*, where the Paduan physician proclaimed in the *differentia 7* that morality and medicine had nothing in common, for the latter concerned *res naturales* and not virtues – indeed, doctors, made arrogant by their professional rise and subject to the astrological influence of Scorpio and Mars were anything but paragons of virtue. What mattered, according to Pietro, was that the doctor should endeavour to behave properly and have virtuous habits (again listed, however, as was traditional).[21]

A synthesis – between traditional motifs derived more or less directly from ancient thought and new ideas developed at the European universities – was provided at the end of the Middle Ages by the work generally regarded as the first thorough reflection on medical ethics: Gabriele de De Zerbi's *De cautelis medicorum*.[22] Zerbi's work, which in fact drew largely on Haly Abbas's *Pantegni* in the Latin translation by Stephen of Antioch and Niccolò Falcucci's *Sermones medicinales*, reiterated the moral and professional qualities required of the doctor as established by the post-Hippocratic medical tradition. But it continued along the path begun by the fourteenth-century doctors by stating the needs and requirements of a professional community. Zerbi dwelled in particular on the indispensable use of diagnostic experience and practice, the need for revision of the *auctoritates*, innovation, and the usefulness of collective medical intervention: themes to which the reflection of previous centuries had alluded only briefly.

Concurrently with moral instructions on the general behaviour that the doctor should adopt, discussion developed on the qualities that the doctor should exhibit when dealing directly with patient. Besides individual instructions which, like those regarding virtues and etiquette, alternated between precepts inspired by common sense and attention to practice with therapeutic consequences, two main stances can be identified, both of them often present in authors' recommendations. The first emphasised that the doctor's behaviour towards the patient, and those at his or her bedside, largely determined the evaluation made of the doctor's dignity, as well as the likelihood of his being sued and consequently not paid. In this case, the procedure was based on professional stratagems designed to give the doctor superiority over the patient (never completely achieved by the mediaeval doctors until the full affirmation of scholastic medicine): more oriented towards this attitude are, for example, the works of Albert de Zancariis and Henri de Mondeville.[23] The other stance, which stemmed from greater awareness and more markedly therapeutic-ethical considerations, paid more explicit attention to the patient's interest – as in the third *lectio* of Arnald of Vilanova's commentary on the first aphorism of Hippocrates.[24] These, however, were not conflicting prescriptions: rather, each of them expressed legitimate concerns which the doctor had to resolve – especially when treating patients – and they condensed many issues inherent to the doctor-patient relationship.

The dilemma between protecting against failure and safeguarding the patient's interests was particularly apparent in the event of extremely severe illness or a prognosis of death. Galen had argued that the doctor should not concern himself with 'terminal' diseases; and this precept was widely resumed by mediaeval physicians (e.g. Bernard de Gordon and Henri de Mondeville).[25] This was not a response to the problem of therapeutic obstinacy (non-existent at that time); rather, it was a relinquishment of treatment that might jeopardize the medical practitioner's credibility, or indeed provoke accusations of negligence. Yet this instruction was contrary to the elementary principles of human compassion and Christian charity. Whilst from the thirteenth century onwards the Church sought to 'monopolize', at least in principle, management of the last phase of life,[26] it is also true that Christian thought, first at the time of the Fathers of the Church and then in the reflections of theologians, emphasised that the physician must not abandon the dying person. His presence, although it could not change the course of events, was comforting to the patient[27] and could serve to alleviate his or her pain.

Polemicists against doctors accused them of fleeing the sick in the case of severe illness. Well-known, for example, are the reports of chroniclers during the plague of 1347: suffice it to cite the proem to Giovanni Boccaccio's *Decameron*. These accusations, however, should be partially tempered. It is true that medical thought after Hippocrates prescribed that the terminally ill or dying should not be treated; but other sources show a different reality. It seems that in some cases doctors directly treated plague victims, and some treatises even stipulated the duty of doctors to care for the sick – in some cases specifying that they should treat plague victims as well.[28] An indirect example is provided by the analysis conducted by S.K. Wray of the wills of Bolognese townspeople, which show that health practitioners (professors at the *Studium*, practising doctors, surgeons and *barbitonsores*, even some medical students) remained with their patients until death.[29]

Of course, this is the usual discrepancy between theory and reality (this time, at least in a positive sense) which also applies to the doctor's behaviour towards the patient.

Communicating with the patient

Besides strictly diagnostic procedures, it is dialogue with the patient that has attracted the greatest interest among doctors in regard to their relations with patients. Anamnesis is based on questions that doctors put to patients, and the interpretations that they should give to the replies, in order to reconstruct not only the course of the disease and its symptoms but also the patient's lifestyle and general circumstances, his or her receptiveness to care, and more or less unconscious beliefs. In dialogue with patients, doctor can demonstrate interest in them, thereby reassuring them and putting them at their ease. All this must be done before the typical acts of diagnosis begin: in particular, according to some authors, before taking the pulse, so that the patient's excessive agitation does not compromise the operation.[30]

The doctor must also ensure the confidentiality of what the patient tells him or her – the Hippocratic *Oath* already stressed the importance of discretion.[31] This is a rather obvious injunction, but it is essential for establishing a trust relation whereby the patient obeys the doctor and the therapy is successful (see below). This 'right to privacy' seems to have been partly overridden in the last centuries of the Middle Ages by the public responsibilities increasingly invested in doctors.[32]

Much more complex is the issue of whether, to what extent, and how to tell the truth to patients about their condition and their likelihood of recovery (which should not be confused with informed consent).[33] In accordance with the Galenic precept that the physician is the friend of truth, also the mediaeval doctors pondered on the extent to which truth-telling might be avoided and for what purpose (Galen had argued that the criterion was the patient's mental state: if he or she was timid and frightened, the doctor could lie to give reassurance). With the therapeutic lie (or simulation) deemed acceptable, there arose issues, like that of the placebo, which concerned the patient's mental state (see below). The Hippocratic corpus already comprised a well-known example of therapeutic simulation, which was also reported by authors such as Urso of Salerno, Michael Scot, and Arnald of Vilanova.[34] In general, the principle was that of *cautela* (caution): prudence in promising recovery, and prudence in the prognosis, which must be pronounced with delicacy, but also with subtlety, ambiguity, and vagueness.[35]

The issue of truthfulness became particularly problematic in the case of fatal prognosis. Part of the problem related to the credibility of the doctor (positions on the matter were discordant: according to Bernard de Gordon, a mistaken prognosis of cure was less risky for the doctor because it was less dishonourable; by contrast, Albert de Zancariis deemed it more convenient for the doctor to venture a fatal prognosis because in the event of recovery the error would be less severe and the doctor might also be credited for the unexpected outcome).[36] The spectre of diagnostic and/or prognostic error constantly loomed; but it was mainly to safeguard the patient's peace of mind, which was necessary for his or her well-being and course of treatment, that doctors considered lying to the patient to be a lesser evil than the naked truth. Some – for instance Urso of Salerno and William of Saliceto – were adamant that the patient should not be given information that might cause him or her to sink into despair (or, conversely, that a lie was admissible if it served to induce positive reactions, as recommended by Arnald of Villanova).[37] Others, such as Albert de Zancariis, envisaged answers that differed according to the extent that the doctor was certain of the prognosis, which made it possible for the whole truth not to be told to the patient but clearly stated to his or her relatives.[38] Also Arnald of Vilanova recommended not lying to the patient's friends and relatives, but rather telling the truth to them in vague terms.[39] Gabriele Zerbi drew a distinction which summarized the positions expressed by medical thought from the classical age onwards. Whilst from the moral and speculative point of view the truth was essential, in the doctor's direct relationship with the patient he must be guided by what has been termed 'the principle of hope': above all, the doctor must keep the hope of recovery alive, and therefore not manifest doubts, and possibly even lie – a precept, however, which had already been expressed in Hippocratic *Decorum*.[40] But this attitude could have serious consequences by preventing the patient from preparing fittingly for death and thus endanger the salvation of his or her soul. A possible remedy for this risk were the canons inaugurated by the Fourth Lateran Council of 1215, and refined by subsequent councils,[41] which obliged the doctor always to summon a confessor before the examination (not afterwards, so as not to cause the patient's despair). However, it appears that only in some cases did doctors, at least theoretically, consider these obligations. This is the case of *De cautelis medicorum*, a text attributed to Arnald of Villanova, but which Michael McVaugh has shown to be at most from the twelfth century and, in fact, a revival of the *De adventu medici ad egrotum* attributed to Arcimatteo of Salerno.[42]

In communicating with the patient, the doctor must be gentle and delicate, and he must be able to speak in parables (without fear of a contrary opinion, for even Jesus had spoken in parables). He must therefore use cautious and vague language inspired by prudence, but also know how to explain technical terminology to the patient.[43] Moreover, he must also know how to listen: to obtain information useful for diagnosis and prognosis, and also to enable the patient's involvement, since this might have psychological benefits.[44] The dialogue with the patient has several consequences: informative for the doctor, psychological for the patient, but also, as we shall see, curative ones. Yet, although it is a dialogue inspired by rhetoric, it must not be vain and pleonastic because, as Arnald of Villanova declared, illness is defeated not by words but by facts.[45]

Passions and accidents of the soul: therapeutic strategies

The doctor must conduct the examination in a different manner for each patient.[46] Whilst this was primarily required by the individuality of each disease, it also stemmed from the need to consider the patient's character and mentality: a key condition for both soothing the mind and making the therapy effective – as Galen had already pointed out in his commentary on *Epidemics*. During the examination (and also before it, if the doctor had been summoned by a messenger), the doctor should be careful to understand the patient's passions and act accordingly. The influence of the passions was a broad topic extending beyond medicine with which doctors became closely acquainted during their training. As part of the six Hippocratic *res non naturales* influencing the state of health, also the passions – which mediaeval doctors preferred to call *accidents* of the soul in order to separate them from the moral sphere[47] – were among the factors that doctors should monitor, besides diet, evacuations, and so on.[48]

In practice, this meant being able to relate to an individual who, under the circumstances, was in a particular psychological and emotional, as well as physical, state. Thus a text attributed to Soranus of Ephesus but datable to the ninth century recommended that, after the questions asked to reconstruct the patient's case history, the doctor should halt for a moment "lest the patient has been terrified through timidity or awe at the presence of the physician, or lest he has been upset by his suffering or wakened from sleep. (Give him an opportunity) to compose himself."[49] The patient should be calm so as not to compromise the diagnostic procedures: in particular, one of the mainstays of medical practice, measurement of the pulse, might be affected by a state of agitation.[50] The tranquility of the patient also had physiological effects, not just emotional ones: the fear of death caused a constriction of the heart, while a hopeful attitude expanded it, allowing the better circulation of the spirits which strengthen the body and help in relieving pain and abating the disease. The doctor must therefore always bear in mind that the conditions created by the patient's hope are more effective than his therapeutic actions – as affirmed by a well-known adage of Avicenna.[51]

Whilst attention to the patient's emotional state was important for *physici*, it was even more so for surgeons, both because of the bloodier curative techniques employed, and because of the more obvious damage in the event of error. Guy de Chauliac repeatedly declared that, if possible, the surgeon should let the patient choose the therapeutic instrument to be used. He emphasised that, in his experience, patients preferred caustication to cauterization, which was usually more frightening.[52] The patient should therefore not see surgical instruments, flowing blood, and so on.

In addition to the manner and content of the dialogue, and with the possible partial or complete omission of the truth, the doctor should contrive to achieve a positive psychological state with other devices: he should pamper the patient by, for example, indulging his or her tastes in food; gloss over certain omissions; prescribe a treatment that was less beneficial than one that the patient did not like but the enjoyment of which would have a better effect, especially during convalescence; ensure that the patient was surrounded by people of the same age and interests, so that they could converse pleasantly and enjoy themselves.[53] This is why the theme of the accidents of the soul was present in the *regimina sanitatis*, and why in treatises on the plague one of the most common suggestions to prevent infection or to accelerate recovery was to create a cheerful atmosphere by means of music, dance, and games. In the *Speculum medicine*, a compendium of medical practice composed in circa 1300, Arnald of Vilanova, while stressing that explanation of how the passions influence the body was not of prime interest to the doctor, furnished a physical synthesis centred on the physiological movements caused by the passions (such as expansion and contraction of the organs, heating and cooling, etc.) already present in Urso of Salerno.[54] Among the various passions, only joy was universally recognized as a cause of positive effects but, as always, with the moderation characteristic of all mediaeval medical thought.[55]

Also the use of charms or amulets was considered, the aim being to create a favourable mental state in the patient. These reflections, which originated from classical medicine and philosophy and from Arabic works, depended on conceptions of the relationship between mind and body. Even doctors more concerned with the physiological aspects of the body and medicines acknowledged the utility of other devices which induced a positive psychological reaction in the patient. In certain respects, this was a theory that anticipated the contemporary one of the placebo effect. The most influential treatise on mediaeval doctors in this regard was *De physicis ligaturis* (also known as *De incantatione*) by the Melchite Christian Qusta ibn Luqa (known in the West as Costa Ben Luca), who was active in the second half of the ninth century.[56] The work is a short treatise in the form of a letter, and it is one of the first translations from the Arabic produced in the Latin West. In all probability, it was first translated by Constantine the African, who was undoubtedly familiar with the treatise, before it spread throughout mediaeval Europe. Drawing on Greek thought, from Hippocrates to Plato, and also on Indian thought, Qusta Ibn Luca theorized something very similar to the concept of the placebo effect. He referred mainly to the use of objects (amulets, stones, etc.), but these the mediaeval doctors extended to include formulas, incantations and prayers,[57] as well as medicines and drugs. All these factors could provoke a psychological reaction with evident positive effects on the body, even if their cause was inexplicable. From them also derived the importance of the relationship between the doctor and the patient, which was crucial not only for philanthropic, ethical, or emotional reasons but therapeutic ones as well. Not coincidentally, the last great doctor of Salerno, Urso, considered the essential qualities of the good doctor to be experience and study, but also charisma.[58] It was the doctor himself who, by inducing complete trust in the patient, became an active part of the treatment on a par with a herb or an amulet – as well summarized by the title of an important article by Fernand Salmón: "The Physician as Cure."

Doctors did not generally attribute therapeutic power to words in themselves; rather, they believed that the benefit sprang from a concatenation of causes/effects from the doctor to the patient which generated a psychosomatic reaction. It was Urso of Salerno who furnished the first complete explanation – one which was substantially the basis of medical notions in subsequent centuries. Because it is not words in themselves that heal (for otherwise anyone could utter them and obtain a cure), Urso argued, it is the trust relationship that arises between the healer and the patient that makes magic formulas and spells successful. This may come about, Urso continued, for various reasons. The first is the nature of the utterer of the words: in this case, through some sort of 'contagion', the spirits emitted by the doctor purified the air, which on being inhaled by the patient, purified him or her as well. Or words had a soothing effect on the sufferer, causing a reaction between the passions and the body.[59] For doctors, the use of speech was only one instrument among others; nor, according to Arnald of Villanova, was it the principal one, as seen: "Convenit esse medicum efficacem in opere, non loquacem."[60]

From the thirteenth century onwards, even in reflections on the curative power of words, it was the theme of trust that most interested doctors. Trust was considered an imperative, in the sense of being a precondition that founded, almost created, the doctor-patient relationship. This in fact was not just trust in the doctor's professional abilities: also involved was a reciprocal recognition as human beings that reduced the asymmetry inherent in the doctor-patient relationship. It was above all through dialogue that the two parties to the relationship gained the knowledge of each other indispensable for creating trust.

Expressed in the Hippocratic *Aphorisms* ("Est fiducia etiam infirmorum de eo committendi se illi vehementior et de quo confidunt infirmi, et in cuius manibus se committunt ipse sanat plus egritudines")[61], and developed by Galen's commentary, both studied at the universities, the patient's trust in the doctor was the fulcrum around which rotated the entire array of patient-doctor relations; and it was an indispensable therapeutic instrument because of its effects on the patient. This contention was the point of departure for subsequent reflections by doctors. It has been pointed out[62] that the early mediaeval and Salerno texts treated the theme of trust in substantially negative terms: they seem to have taken a conflicted relationship for granted. These texts urged doctors to use stratagems that would secure the trust of patients depicted as generally mistrustful of doctors. It is also for this reason that recommendations regarding moral virtues and etiquette were so central to those texts. By means of the repute resulting from his morality, behaviour which emphasised his dignity, and his somewhat theatrical therapeutic gestures, the doctor put the patient, and his or her family members, in a position of inferiority mitigated by his humble and affable demeanour: in short, he adopted what today would be called a paternalistic attitude in order to render the patient submissive. This climate of (at least apparent) distrust was also due to the ambiguous social status of the early mediaeval doctors, who, in the absence of an established educational system, were liable to either accusations of crookedness or the risk of failure.

These issues did not diminish in importance as the centuries passed (already mentioned has been the university doctors' concern to protect their dignity and safeguard their fees); but the advent of university education gave rise to both professionalization, accompanied by the social ascent of the doctor, and more thorough theoretical analysis. The doctor's almost conflicted need to win the patient's trust in order to emphasise his role seems to have given way to the therapeutic need to gain that trust. Trust, as said, had beneficial hope-generated effects on the organism (e.g. according to Petrus Ispanus); but it also engendered a different attitude towards the doctor, whose prescriptions his patients more willingly followed because they trusted him (e.g. according to Mauro of Salerno, Taddeo Alderotti, Mondino de Liuzzi).[63] If the therapeutic action was to be effective, therefore, it was essential that the patient should trust the doctor. The first task of the latter was consequently to create trust with words and gestures that "were not mere adornments used at random but potential healing devices that needed to be carefully monitored, because they had a powerful effect on the patient's physical condition."[64] Showing the patient that the doctor cared about his or her condition also produced trust. Accordingly, Arnald of Villanova, in the third *lectio*, recommended frequent examinations of the patient (also useful for obtaining an accurate diagnosis).[65]

The doctor therefore had to interact with the patient in a manner that, although it was not that of *amicitia* (detachment was necessary to ensure respect for the actors' different statuses), was undoubtedly of empathic type. According to Peter of Abano, if a doctor was to obtain *confiance*, and the consequent efficacy of his words (which were not just formulas but also therapeutic prescriptions, and vice versa), he should be affectionate, credible, and charismatic ("animae fortis impressive" – which recalled what Urso of Salerno had already written).[66] Such behaviour, which did not fully coincide with either Christian or secular norms, was the result of medical thought, and it can therefore be regarded as reflecting what was, at least embryonically, a professional ethic.[67]

The patient as the subject in the relationship

Trust between doctor and patient determined the prime characteristic required of the ideal patient (besides the etymologically-related *patience*): namely obedience. This did not spring, at least not in the medical thought developed at the universities, from the power relationship between doctor and patient, but rather from the trust that the doctor was able to obtain from the patient. Obedience was the prime quality required of the patient, but trust in the doctor had to come first.[68]

From Galen's commentary on Hippocrates ("Non solum oportet facienda ex parte tui fier, sed etiam tibi infirmum obedire, neque in aliquo decet obviare eum")[69] onwards, obedience was the main virtue required of the patient: if he or she did not obey the doctor, the therapeutic relationship was at risk because, as Arnald of Villanova wrote, obedience delegated intervention on the body to action by the doctor in the patient's interest.[70]

Resumed from the pre-Salerno texts, the theme of obedience was central to the doctor-patient relationship also in the commentaries of the university professors, albeit with different nuances. Whilst, as said, in the older texts it was the doctor who had to prove himself trustworthy, and thereby obtain the patient's obedience, in the works of scholastic medicine a shift came about whereby obedience became an essential prerequisite for the relationship, together with hope and the desire to recover: in fact, trust became reciprocal because the doctor had to trust the patient to perform his or her role as well as possible.[71] The master of Montpellier *Cardinalis* emphasised that specular to the doctor's knowledge and experience was the obedience of the patient ("et oportet egrum facere quam oportet ut scilicet sit obediens"), a concept also affirmed by Taddeo Alderotti, a Bolognese master, who established the qualities required of the two actors: *peritia* for the doctor, *obedientia* for the patient. Moreover, suitability was required of assistants and appropriateness of external factors (a fourfold distinction resumed on several occasions, for example by Ugo Benzi, Arnald of Villanova and Henri de Mondeville),[72] which reveals that in the Middle Ages the doctor-patient relationship was still regarded as a set of relations involving several actors.[73] Once again apparent in the shift from the early mediaeval emphasis to that of scholastic medicine is the process of social and professional ennoblement and the more profound reflection made possible by the greater availability of medical texts.

The strategies employed by the doctor to obtain trust were also intended to ensure that the patient would obey him: a theme reiterated so often as to suggest that disobedience was rather widespread among the sick. It was due to a deep-rooted distrust in health practitioners constantly wavering between art and sorcery, but also by the fact that, once on the road to recovery, patients tended to feel that they no longer needed a doctor, or considered his prescriptions too restrictive (an unmediated mechanism that at the end of the nineteenth century was termed 'psychological reactance');[74] or worse, they thought that they knew as much as the doctor (for which reason the doctor should not be over-informative to the patient and rather vague in his explanations).[75]

The ancient metaphor (first propounded by Hippocrates and Galen, and resumed in Arnald of Vilanova's commentary) of the doctor as a sailor who must be able to adapt his actions to changes in sea and wind conditions, and must maintain constant control over the ship, seems to refer, *inter alia*, to a power relation in which the doctor was the only actor. The patient, who had to place himself in the hands of the doctor by virtue of the obedience due to him, seems to have been relegated to an entirely passive role. However, I agree with the contention of Marilyn Nicoud and Fernand Salmón that the obedience of the patient was an integral part of the therapeutic relationship, and that, in mediaeval medical thought, the patient was not perceived as such, but rather as an actor of equal standing with the doctor, albeit in a position with different characteristics.[76] The patient was an actor who, like the doctor (and assistants and external causes), had responsibility for achieving the shared objective (healing). Hence the obedience required was not mere submission to the doctor, but rather performance of the patient's role in the relationship, and an acceptance of the doctor's expertise most probably the result of outright negotiation between them.[77] It was only after this allocation and acceptance of roles and responsibilities – almost a 'moral contract'[78] – that the *sick person* became a *patient*.

The image of an entirely passive patient also derives from the nature and quantity of the sources reached and/or used to reconstruct the doctor-patient relationship. There is no doubt that historians have long concentrated on the role and perspective of doctors. This has been due to historiographical choices, but also to the fact that almost all the sources are works by doctors themselves. More recent research, however, has shown that, if one reads between the lines of medical texts and extends the range of sources to include non-medical texts, it is possible to shed clearer light on the figure of the patient.[79] This was a figure not silent and inactive, nor even invisible,[80] but which performed its own role in the doctor-patient relationship and provided important information about it.

Prescriptions on how to conduct physical examinations had already highlighted the need to have patients talk. From their narratives, the doctor could compile the case history, but also a profile that included the patient's mental state, emotional characteristics, and perception of the disease. One might say in general that the doctor can use the patient's account to 'establish' disease and illness, thereby objectifying the malady so that it is knowable and therefore treatable.[81] The patient's narrative is a crucial part of the doctor-patient relationship: through it the patient communicates his or her symptoms, fears, and deeply-held convictions, and also actively participates in the relationship. It is not easy to find instances of these narratives in medical texts, mainly because of a scientific exigency (or the lack of a cultural one). It is not that the mediaeval physicians considered the patient's narrative to be unimportant: Taddeo Alderotti wrote that it was essential to listen to and construe the patient's account, but it was not necessary for the same account to be recorded in writing or interpreted in medical works. This partially explains the silence of the sources (although, it should be noted that interest in the individual gradually increased, especially in cases deemed extraordinary).[82] Rare depictions of patients appear in *consilia*[83] and *practicae*, but here the references are descriptive and broadly interpreted by the doctor, who tended to turn them into general *rationes*.

Non-medical sources can shed light on the patient's perception of disease and medicine especially in regard to the upper classes (a well-known example is the description of his cataract operation written by Gilles le Muisit in 1351).[84]

Marilyn Nicoud, for example, has recently addressed the issue by analysing the correspondence of the Visconti-Sforza court.[85] This was a particular context, that of the prince, which involved state interests; and it was a privileged one because it concerned patients who could rely on the constant support of a team of doctors.[86] Given the distinctiveness of the source, most apparent is the almost obsessive attention paid to issues of health and illness, with constant monitoring between family members and their entourages, as well as a non-specialist appropriation of medical knowledge which was probably adopted by a wider, though still small, social group. This entailed, on the one hand, the borrowing, or imitation, of language similar to that of practitioners (which partly restricts the scholar's ability to interpret the patient's point of view), and on the other hand, the further undermining of trust in the doctor and his prescriptions (because, as said, the patient could know just as much as the doctor). But it was also symptomatic of an attitude which, though still restricted to a context as specific as the court, reflected the medicalization of not only society but also individual psychology throughout the lifetime (which, moreover, was already present *in nuce* in the *regimina sanitatis*): the constant presence of the doctor was reassuring and perceived as almost a 'protective presence.'[87]

Centred instead on sources produced directly by university doctors are recent studies by Fernando Salmón, which show that, upon careful reading, even technical texts can yield information concerning the patient's perception.[88] Salmón examines two particular cases: discourse on pain and discourse on mental illness, since in both of them the patient's narrative is absolutely central (another example is that of headache analysed by Jamie McKinstry).[89]Attempts to define various categories of pain, so as to create a medical system as universal as possible, have shown that it is impossible for doctors to interpret pain without the sufferer's narrative (already in the tenth century an anonymous Salerno author advised doctors to interrogate patients scrupulously about the pain that they felt);[90] aseptic medical definitions, which did not report or at least convey the patient's words, were largely inadequate. The physician should endeavour to transpose an often periphrastic account (which in a sense recalls the parables that the doctor was advised to use) provided by a sick person – moreover, one not necessarily educated – seeking to describe pain in his or her own words. In this context, therefore, according to Salmón, there was an undeniable two-way interaction, not only between the doctor and the patient, but also between the knowledge of the doctor and the knowledge of the patient. A medical language of pain derived from the transposition by doctors of the accounts of patients. In short, it resulted from a lexical and semantic negotiation that took place during the encounter between doctor and patient.[91] The theme was not a new one: Galen had already explicitly recognized, in *De interioribus*, that a terminology of pain should necessarily include also the patient's vocabulary. The scholastic doctors, however, seem to have overlooked this point (not out of ignorance, because Galen's treatise was one of the texts most widely used for teaching purposes).

Differently, in the case of mental illnesses the narrative of the sufferer is fundamental even the first phase of diagnosis, i.e. in definition of the illness. The therapy necessarily ensues from the patient's account. In the mediaeval medical treatises, the difference between the two cases consisted in the use of this narrative: in the case of pain, the account seemed to serve 'only' in the individual relationship with the individual patient, and therefore for diagnostic and therapeutic purposes, but it became invisible in the creation of a theoretical medical discourse.[92] In mental illness (the case considered by Salmón is that of melancholy), the dialogue between doctor and patient can by its nature only take place within a linguistic system determined by the patient and which is not fully translatable into technical language (i.e. with tendentially universal value).

The apparent, at least theoretical, lack of interest shown by scholastic doctors seems to have been due to the ennoblement of *ars medica* accomplished at the universities, with the consequent hierarchization of knowledge; somewhat like the manner in which early mediaeval doctors emphasised the discrepancy between their knowledge and that of patients and, in general, non-doctors. It was Taddeo Alderotti who dwelled most closely on this issue in his commentary on Hippocratic *Regimen acutorum*. Contrary to Hippocrates – who had criticised doctors who gave excessive importance to the patient's account because the symptoms of the same disease are perceived differently from individual to individual, and because sick people tend to exaggerate their condition due to anxiety – Alderotti argued that the patient's narrative was of great help in medical practice and should be considered veracious. It was in regard to efficacy for the creation of a medical discourse that Alderotti regarded the symptoms described by the patient as too closely bound up with individual experience, and above all dependent on an erroneous knowledge system – that of the lay public – opposed to the doctor's real expertise.[93] Apparent here is an attempt to posit as the subject of the doctor's knowledge the 'objectified body'[94] characteristic of medicine's transition from *ars technica* to *scientia*; but this had to be nuanced with reference to the patient's discourse at least in therapeutic practice.

A contractual relation

Turning from speculation to practice, it seems that in some cases the patient's point of view was crucial for therapeutic assessment.

The 'non-passivity' of the mediaeval patient as a party to the relationship, as well as his or her voice, also emerge from the conception of health – or better of recovery – which underlay the request for treatment by a physician (whilst, at least apparently, more immediate was determining the success, or failure, of a surgeon's performance).[95] It has been pointed out that it was not customary to summon a doctor for any malady whatever: hence the presence of a doctor meant that the illness was, or was perceived to be, severe or disabling. Whilst doctors could consider, on the basis of the theory of humours and complexions, that healing was the temporary restoration of a physiological balance,[96] for the patient cure often meant restoration of a condition that existed prior to the onset of what he or she he perceived as illness, as well as the possibility of resuming the functions and activities that the illness had halted or made more difficult.[97] This is evidenced especially by so-called 'recovery-pacts' – notarial deeds with which the two parties (doctor and patient) committed themselves reciprocally before the provision of medical care. The different points of view are evident, for example, in a contract of 1226 between a doctor and a visually impaired patient, where the former defines cure as the removal of flecks and blurs from the eye, and the latter as resumption of his affairs.[98]

Although contracts between doctor and patient pertain mainly to the late Middle Ages, instances of them can be found much earlier. In fact, the first examples date to the *Leges Visigothorum*, enacted between the second half of the fifth century and the second half of the sixth, and which, particularly in *Leges III* and *IV Antiquae*, made direct reference to doctor-patient contracts. Moreover, agreements of this kind were also envisaged by coeval Roman laws.[99] Put briefly, the relationship was specified by private arrangement between the two parties and contracted prior to the treatment. Gianna Pomata has called such contracts 'promises of cure' because the doctor agreed to care for the sick person, who for his or her part specified the result that the doctor must achieve, and which the practitioner accepted by signing the contract. Moreover, almost always specified was the duration of the treatment, the exceeding of which was likely to invalidate the contract. In the event of failure or relapse, the patient was not obliged to pay the doctor. Suffice it to cite just one example among the many: in 1244, the doctor Rogerio promised the Genoese weaver Bosso, struck with disabilities in his hand, foot and mouth, that "within one month (I shall cure you) so that you can feed yourself with your hand, cut bread, put on your shoes, and walk and talk better than you do now."[100] This type of contract, although not always well regarded by doctors, was widespread, accepted, and considered legally valid, so that in the event of accusations of failure to fulfil the contract, the judge could summon other doctors to conduct an assessment, and if the doctor was found to be in default, order him to return his fee or not to charge it. Established at the same time, at least implicitly, were the obligations of the patient: in the case of disobedience, real or presumed, the doctor could plead 'not guilty' to the charge of therapeutic failure.[101]

Because negative events attract most attention, and leave more written documentation, it is likely that legal proceedings between doctors and patients were a possible outcome, but not necessarily the most frequent one, of doctor-patient relationships. The cure contract, rather than establishing a 'doctor versus patient' relationship, was used in the absence of a licence-based system of access to the profession – which slowly developed during the last centuries of the Middle Ages – to protect the initially weaker party (the patient) from inept or dishonest doctors, and to establish parity, at least formally, between the two contracting parties.[102]

The contract also stipulated the amount of the fee. The topic of the remuneration of doctors is an extremely broad one, because it also involves philosophical and theological issues which will not be addressed here.[103] To be stressed is a gradual social and cultural acceptance of medical payment, which for some doctors was the embodiment of the patient's trust. For this reason, Henri de Mondeville, who most thoroughly discussed the issue of payments, believed that the doctor must be paid before the treatment.[104] However, as we have seen, the contracts established precisely the opposite. Of course, the figure of the doctor became professionalized from the central Middle Ages onwards: consequently, in a society deeply imbued with a 'mercantile ethic', paying for a professional service became increasingly accepted. Whilst the lexical shift from *honorarium* (a 'gift' determined by satisfaction with the service) to *salarium* (a fixed sum calculated on the basis of the time, quality and success of the service) seems to imply an outright change,[105] the reality is more nuanced. The 'recovery-pact' can perhaps be considered an instrument midway between an *honorarium* and a *salarium*, since the latter implied that the payment should be made for the service itself, not for its success. Whilst de Mondeville (who, however, was a surgeon and therefore more constrained by the evidence of the result of his performance) argued for payment in advance, other doctors, such as Peter of Abano and Gabriel Zorzi, affirmed the *ratio* of 'recovery-pacts' by maintaining that the fee should be calculated according to the efficacy of the treatment.[106]

The matter of payment (in which, however, the aspect of the practitioner predominated over that of the healer) was intuitively part of the doctor-patient relationship, but as pointed out by Michael McVaugh, it was not a theme central to mediaeval medical thought,[107] and moreover also concerned issues extraneous to it. What is certain is that, according to the Hippocratic moral precepts, the doctor must not be avaricious, nor should his purpose be enrichment (so that, for example, he must not prolong the treatment in order to obtain a larger fee);[108] but established at the same time was the lawfulness and necessity of his fee. Only the indigent, the *pauperes*, could be treated for free: an act of charity that re-projected the mediaeval doctor on the scenario of *christianitas*.

Notes

1 Luis García-Ballester, *Ethical Problems in the Relationship between Doctors and Patients in Fourteenth-Century Spain: On Christian and Jewish Practitioners*, in Samuel S. Kottek and Luis García-Ballester (eds), *Medicine and Medical Ethics in Medieval and Early Modern Spain. An Intercultural Approach* (Jerusalem: Magnes Press, 1996), 11-32; see Michael R. McVaugh, *Medicine before the Plague. Practitioners and their Patients in the Crown of Aragon 1285-1345* (Cambridge: Cambridge University Press, 1993). See also Klaus Bergdolt, *The Discourses of Practitioners in Medieval and Renaissance Europe,* in Robert B. Baker and Laurence B. McCullough (eds), *The Cambridge World History of Medical Ethics* (Cambridge: Cambridge University Press, 2008), 370-8. Most recently published Mariacarla Gadebusch Bondio (ed), *Medical Ethics. Premodern Negotiations between Medicine and Philosophy* (Stuttgart: Franz Steiner Verlag Wiesbaden Gmbh, 2014).

2 See Jole Agrimi and Chiara Crisciani, *Malato, medico e medicina nel Medioevo* (Torino: Loescher, 1980), 33-6; Ead., *Carità e assistenza nella civiltà cristiana medievale*, in Mirko D. Grmek (ed), *Storia del pensiero medico occidentale. Antichità e Medioevo* (Roma-Bari: Laterza, 1993), 217-59 (cit. on p. 224); Darrell W. Amundsen, *Medical Ethics, History of Europe. I. Ancient and Medieval. C. Medieval Christian Europe,* in Stephen G. Post (ed), *Encyclopedia of Bioethics* (New York: Macmillan Reference, 2004), 1568-83: 1569-70.

3 Luis García-Ballester, *Medical Ethics in Transition in the Latin Medicine of the Thirteenth and Fourteenth Centuries: New Perspectives on the Physician-Patient Relationship and the Doctor's Fee*, in Andrew Wear, Johanna Geyer-Kordesch and Roger French

(eds), *Doctors and Ethics: the Earlier Historical Setting of Professional Ethics* (Amsterdam-Atlanta: Rodopi, 1993), 38-71: 39; Michael R. McVaugh, 'Bedside Manners in the Middle Ages', *Bulletin of the History of Medicine*, 71:2 (1997: summer), 201-23: 205-6.

4 See Danielle Gourevitch*, Le triangle hippocratique dans le monde gréco-romain: le malade, sa maladie et son médecin* (Roma: Ecole française de Rome, 1984), 251-77; Jacques Jouanna, *La lecture de l'éthique hippocratique chez Galien*, in Hellmut Flashar and Jacques Jouanna (eds), *Médecine et morale dans l'antiquité. (Entretiens sur l'antiquité classique, 43)* (Vandoeuvres-Genève: Fondation Hardt, 1997), 209-44: 218-40.

5 For a selection of 'pre-university' texts on these topics see Loren C. MacKinney, 'Medical Ethics and Etiquette in the Early Middle Ages: the Persistence of Hippocratic Ideals', *Bulletin of the History of Medicine*, XXVI: 1 (January-February 1952), 1-31, Agrimi-Crisciani, 1980, and Faith Wallis (ed), *Medieval Medicine. A Reader* (Toronto: University of Toronto Press, 2010), 387-430.

6 Carlos R. Galvão-Sobrinho, 'Hippocratic Ideals, Medical Ethics, and the Practice of Medicine in the Early Middle Ages: The Legacy of the Hippocratic Oath', *Journal of the History of Medicine and Allied Sciences*, 51:4 (October 1996), 438-55.

7 MacKinney, 1952.

8 *Ibid.*, 11-2

9 On this particular aspect see Chiara Crisciani, 'Éthique des *consilia* et de la consultation: à propos de la cohésion morale de la profession médicale (XIIIe-XIVe siècles)', *Médiévales*, 46 (printemps 2004), 23-44.

10 García-Ballester, 1993*,* 41-2.

11 Text 'K' in MacKinney, 1952, 18.

12 McVaugh, 1997, 203-4.

13 Darrell W. Amundsen, 'Visigothic Medical Legislation', *Bulletin of the History of Medicine*, 45:6 (1971: November), 553-69: 562.

14 See e.g. *Costantini Africani Prologus libri De communibus medico cognitu necessariis locis*, PL, 150, coll. 1563-1564, and *De instructione medici secundum Archimathaeum*, in Salvatore De Renzi (ed), *Collectio Salernitana*, V (Napoli: Filiatre-Sebezio, 1853), 333-49.

15 Chiara Crisciani, *La formazione del medico nel Medioevo: dottrina ed etica*, in Monica Ferrari and Paolo Mazzarello (eds), *Formare alle professioni. Figure della sanità* (Milano: Franco Angeli, 2010), 36-57: 55.

16 García-Ballester, 1993, 44-6.

17 Pierluigi Licciardello (ed), *Guido d'Arezzo, Liber mitis. Un trattato di medicina fra XII e XIII secolo* (Ospedaletto (Pisa): Pacini, 2009), 58-61.

18 Arnald of Vilanova, *Repetitio super aphorismo Hippocratis 'Vita brevis'*, in *Arnaldi de Villanova Opera Medica Omnia*, XIV, eds Michael R. McVaugh and Fernando Salmón, in press. See García-Ballester, 1993, 42-3; Michael R. McVaugh, *Medical Values and Behavior. A View from 1380s Montpellier*, in Gadebusch Bondio (ed), 2014, 73-89: 82 ff.

19 *Guidonis de Cauliaco Inventarium sive chirurgia magna*, ed. Michael R. McVaugh, 2 vols. (Leiden: Brill, 1997), I, 9-10.

20 Fernando Salmón, *The Physician as Cure in Medical Scholasticism*, in Ildiko Csepregi and Charles Burnett (eds), *Ritual Healing. Magic, Ritual and Medical Therapy from Antiquity until the Early Modern Period*, (Firenze: SISMEL-Edizioni del Galluzzo, 2012), 193-215: 212.

21 Danielle Jacquart, *Le medecin médiéval et les bonnes moeurs*, in Gadebusch Bondio (ed), 2014, 47-60: 49-51.

22 Roger French, *The Medical Ethics of Gabriele de Zerbi*, in Wear, Geyer-Kordesch and French (eds), 1993, 72-97; David E. J. Linden, 'Gabriele de Zerbi's *De cautelis medicorum* and the Tradition of Medical Prudence', *Bulletin of the History of Medicine*, 73:1 (1999: spring), 19-37; Jospeh Ziegler, *The Medieval Foundations of Renaissance Medical Ethics: the Case of Gabriele Zerbi's* De cautelis medicorum, in Gadebusch Bondio (ed), 2014, 117-29.

23 Henri de Mondeville, *Chirurgie*, fr. trans. by Édouard Nicaise (Paris: Félix Alcan, 1893); Manuel Morris, *Die Schrift des Albertus de Zancariis aus Bologna 'De cautelis medicorum habendis'* (Leipzig: Ferdinand Peter Nachf, 1914). Cfr. McVaugh, 2014, 79-80.

24 See *ibid.*, 79 ff.

25 Luke Demaitre, *Doctor Bernard de Gordon, Professor and Practitioner* (Toronto: Brepols, 1980), 54; Henri de Mondeville, 1893, 306.

26 For a summary see Tommaso Duranti, *La morte nella medicina bassomedievale (secc. XII-XV)*, in Francesco Paolo de Ceglia (ed), *Storia della definizione di morte* (Milano: Franco Angeli, 2014), 165-81: 172 ff.

27 See e.g. John Chrysostom: Anna Maria Ieraci Bio, 'Produzione letteraria e deontologia del medico in età tardoantica', *Medicina nei secoli. Arte e scienza*, 24/2 (2012), 403-21: 409; see also Amundsen, 2004, 1580.

28 Darrell W. Amundsen, 'Medical Deontology and Pestilential Disease in the Late Middle Ages', *Journal of the History of Medicine and Allied Sciences*, 32:4 (1997), 403-21; Id., 2004, 1580; see also Marilyn Nicoud, *Le prince et les médecins. Pensée et pratiques médicales à Milan (1402-1476)* (Roma: École française de Rome, 2014), 383-471.

29 Shona Kelly Wray, 'Boccaccio and the Doctors: Medicine and Compassion in the Face of Plague', *Journal of Medieval History*, 30:3 (2004), 301-22.

30 E.g. *De adventu medici* e *De instructione medici.*

31 Gourevtich, 1984, 259. On the Hippocratic Oath see Pearl Kibre, 'Hippocratic writings in the Middle Ages'. *Bulletin of the History of Medicine*, 18:1 (1945: January), 371-411, and Galvão-Sobrinho, 1986.

32 Darrell W. Amundsen and Gary B. Ferngren, *Evolution of the Patient-Physician Relationship: Antiquity through the Renaissance*, in Earl E. Shelp (ed), *The Clinical Encounter. The Moral Fabric of the Patient-Physician Relationship* (Dordrecht-Boston-Lancaster: Springer, 1983), 3-46: 43; Nicoud, 2014, 390-8.

33 McVaugh, 1993, 166.

34 Maaike van der Lugt, 'The Learned Physician as a Charismatic Healer: Urso of Salerno (Flourished End of Twelfth Century) on Incantations in Medicine, Magic, and Religion', *Bulletin of the History of Medicine*, 87 (2013), 307-46: 316.

35 See Mariacarla Gadebush Bondio, 'Verità e menzogna nel dialogo fra medico e paziente (XV-XVII sec.)', *I Castelli di Yale*, XII (2012), 71-85: 74, which cites Ps. Arnald of Vilanova; Jacquart, 2014, 52, which cites Peter of Abano.

36 For a summary see Duranti, 2014, 172-74.

37 See Salmón, 2012, 213.

38 Van der Lugt, 2013, 315; McVaugh, 1997, 216-7.

39 Id., 2014, 81.

40 Gadebush Bondio, 2012, 74-5; Ead., *"Speaks True, Who Speaks Shadows". Truth and Lies at the Sick-bed*, in Gadebusch Bondio (ed), 2014, 221-39: 224-5; on Hippocratic *Decorum* see Gourevtich, 1984, 265.

41 See Marie Christine Pouchelle, 'La prise en charge de la mort: médecine, médecins et chirurgiens devant les problèmes liés à la mort à la fin du Moyen Age (XIIIe-XIVè siècles)', *Archives européennes de sociologie*, 17 (1976), 249-78: 255-6.

42 *De adventu medici ad aegrotum*, in De Renzi (ed), 1853, II,74-80; McVaugh, 1997.

43 Crisciani, 2010, 55.

44 See Edward Shorter, *Bedside Manners: The Troubled History of Doctors and Patients* (New York: Simon and Schuster, 1985), 197.

45 Crisciani, 2010, 55.

46 *Quomodo visitare debes infirmum*, in De Renzi (ed), 1853, II, 73.

47 Jacquart, 2014, 58.

48 Salmón, 2012, 206-7; see also Pedro Gil Sotres, Introduction to the *Regimen sanitatis ad regem Aragonum, Arnaldi de Villanova Opera Medica Omnia,* vol. X.1 (Barcelona: Publicacions de la Universitat de Barcelona, 1996), 803-27.

49 MacKinney, 1952, 22.

50 *De adventu medici*; see MacKinney*,* 1952, 26.

51 Van der Lugt, 2013, 315; Avicenna, *De anima* (IV.4): Jacquart, 2014, 49n.

52 *Guidonis de Cauliaco*, 1997, I, 375, 443; see McVaugh, 1997, 218-9.

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Chapter Three

Doctor and patient in the modern age: words, gazes and gestures

Claudia Pancino

> Although the figure of the doctor is that of someone who commands and decides, and likewise the figures of the patient and the attendant are of persons who obey and submit, their purposes and intents should be the same ... Doctors and patients should, with their will and their action, pursue one single end: that of health. Will and action are not incompatible with each other.

This extract from *I Doveri del Medico e del Malato* by the Piedmontese physician Leonardo Botallo, 1565, encapsulates the relationship investigated in this chapter.[1]

Paintings from the past exemplify various aspects of the matter. One of them depicts a doctor scrutinising a phial of his patient's urine. This is the *Visit of the Physician* by the Dutch painter Gerrit Dou (1613-1675). In another image – a hand-coloured engraving – a doctor, standing and elegantly dressed, takes the pulse of a seated man of miserable appearance, in evident pain, and shabbily dressed. This caricature, entitled *The Rich Doctor and the Poor Patient* (ca. 1840), is a work by the French artist Jean Edmé Pigal and the English engraver Joseph J. Jenkins. A similar scene, but in a richer setting, has a woman at its centre: this is *La Dama Ammalata* by the Venetian Pietro Longhi (1702-1785). Finally, there is an engraving, from a seventeenth-century medical text, showing a patient in bed, and seated at the table next to him, a doctor writing with a quill pen on a sheet of paper.[2] Several other artists and illustrators of the time depicted similar scenes.

Doctor and patient in *Errori Popolari*

At the beginning of the seventeenth century it was debated whether medicine was a ‘mechanical art’ or a ‘science’. The question traverses the almost eight hundred pages of *Errori Popolari d’Italia* by Girolamo (Scipione) Mercurio. Published in Venice in 1603[3], the book was written with the intent of emulating Laurent Joubert, a doctor of Montpellier, who had published his *Erreurs Populaires et Propos Vulgaires Touchant la Médecine et le Régime de Santé* between 1578 and 1579.[4]

Mercurio’s reply was obviously that medicine is a science. Indeed, the seven books of his work were conceived and written to prove that contention. Another purpose of the publication was – like all the works in the ‘popular errors in medicine’ genre – to define the medical profession by distinguishing the figure of the doctor from other practitioners of the therapeutic art, and also to defend it from criticism. We consider this testimony first because Mercurio’s collection of ‘errors’ also recounts the medical practice of the time and gives voice to the patients.

Mercurio’s *Errori Popolari* merges illness with the human condition, while it attributes an almost salvationary function to medicine. Man comes naked into the world, and he weeps and sighs as he enters. Throughout life, man is a “prisoner of death,” “slave of doctors, afflicted by diets, murdered by medicines, battered by syrups and enemas, deprived of wine and everything pleasant, disgusted by pap, and confined to bed. Feeling dead while being alive is indeed harsh penance, yet medicine frees us from all these miseries.”

The patient considered by Mercurio is a sick person who is in bed, not “to be more comfortable” but because he is suffering from afflictions “that force him to stay in bed.” The scene of the patient’s room is more or less as follows: the patient lies in bed in his room while the household is in turmoil. “His closest and most affectionate relatives,” “his dearest friends,” “his dear wife,” “his sweet children,” all want to do it their own way “without heeding the advice of doctors, indeed acting against the advice of the doctors.” It is thus that the patient may be killed by his closest kin, who “as crocodiles weep for the man that they are about to dismember”; or – as Mercurio writes on the first page of his book – they act like monkeys which “when with feral tenderness they caress their offspring, squeeze them so tightly that they suffocate.” Medicine, as we know, is something that everyone wants to practise; why, wonders Mercurio, “does everyone want to propose remedies to others?” Because, he answers, “medicine is so lovable that everybody wants to exercise it,” and they do so also for “vainglory” and “curiosity.”[5]

In this regard, Laurent Joubert, on arguing that the medicine was the most widespread of professions, cited in his *Erreurs* an Italian anecdote which started by saying that medicine was the most common profession. Joubert wrote, "It is said that the Duke of Ferrara, Alfonso," asked in idle conversation what was "the trade with the most persons." One said the trade of cobbler, another tailor, carpenter or sailor, yet another peasant or pettifogger. The jester Gonella replied that it was the profession of doctor, and that he would prove it within twenty-four hours. The next morning, after he had bandaged his chin to simulate toothache, muffled up warmly and wearing a nightcap as if he was sick, Gonella left his house and headed for "the palace of His Excellency" by way of Via degli Angeli, where he met numerous persons. Each of them asked what was wrong with him – to which he answered "a terrible toothache." Each suggested a remedy, and if there was a small group of two or three persons, Gonella received at least two or three different pieces of advice. "And so, as he continued along the street, he met no-one who did not recommend a remedy different from the others, each of them saying that his recipe was well-tried, certain and infallible." On his arrival in the lower courtyard of the palace, the scene was repeated. Everyone he met "insisted on giving him a recipe, and they all said that it was the best in the world." When Gonella came before the presence of the Duke and the court physician, therefore, he could declare that he had encountered around two hundred doctors, "Thus in truth well told," wrote Joubert, "was how everyone dabbles in medicine, and there are few persons who do not think that they know a great deal about it – indeed even more than the doctors."[6]

Let us return to Scipione-Girolamo Mercurio, who was highly critical of the competition raised against doctors by charlatans, mountebanks, and also women. In his view, in fact, it was mostly women who believed that they knew more than the others, and even more than the doctor. Of course, he wrote, it was women who took care of the sick; consequently they could dare to pronounce on medical matters: "They want to be philosopheresses and doctresses; women who constantly annoy doctors … harridans … who speak so much balderdash that it makes one vomit."

The patient's wife, sister, landlady, or all the women of the household together, usually made the diagnosis and suggested the treatment. Moreover, they often gave the patient too much to eat to sustain him, or wine and sugar to cheer him. The agitation of the relatives and their ploys to relieve the patient's suffering added to the confusion of visits and chatter at the patient's bedside. Too many visits were to be avoided "because they fatigue the brain and the tongue," but also because there might be persons who were disliked among the visitors and whose presence might distress the patient, or excessively attractive women, which might morbidly disturb the patient's sleep. So common was the unhealthy habit of visiting the sick that in Padua, Mercurio recounts, sometimes even parties were held in their dwellings.[7]

According to Scipone-Girolamo Mercurio, the prime dangers to the patient were his relatives and attendants; but other, perhaps more frightful, dangers were represented by doctors and medicines – those medicines that "give more nuisance in their taking than benefit in healing." Mercurio thus introduced one of his many criticisms of inexpert, untrained, and careless doctors. Furthermore, "negligent care by women," unhealthy habits like not changing the patient's bedsheets or shirt, dirtiness sometimes such "to make statues vomit," together with folk customs and beliefs as rooted as they were harmful, surrounded the patient's disease.[8]

Mercurio provides detailed descriptions of the qualities and skills that a good doctor should possess. They match the requirements proposed by the *galatei* (books on polite behaviour) to which we shall return below. Having selected a doctor, it was essential to trust him, obey him, respect him, and pay him. Then, after the choice of a capable and well-trained – not the kindest – doctor had been made, the doctor/patient relationship proceeded as follows. First, a servant was often sent with the patient's urine to the doctor's house, so that he could determine the severity of the illness. Some doctors – wrote Mercurio – were content with this examination and engaged in 'medical consulting by letter', i.e. conducted more or less intense correspondence with the patient. But it would be better, Mercurio said, especially when inspection of the urine indicated a serious illness, for the doctor to take his horse and ride to the patient's home.[9] Incidentally, in another book, Mercurio recounted the intelligence of his own horse, who was an excellent assistant: "if I drop a glove, he halts; if I exchange greetings with someone, he halts; if I go to visit a sick person at home more than once a month, when years later I ride along that same road, he halts at the patient's door."[10]

Having arrived at the patient's home, the doctor must make his way through agitated and conceited relatives, especially women, and with idle servants who do not even offer him a chair and an inkwell, although he will obviously have things to write. The doctor's reception is usually unsatisfactory and not worthy of his role and functions. "The urine is not prepared, or if they have prepared it, the urine container is filthy." Instead, a chair should be offered to the doctor, and an inkwell and writing paper should be ready. The doctor's time should not be wasted, for he always has a great deal to do. "With diligence," he should find "urine in the chamber pot, or in a very clean glass," so that the time available to him is not wasted on these things, but instead used to "spend time with the patent" and "confabulate," "without being disgusted by these wretched things." Mercurio emphasises that "these errors are indecent in the cities, but in small towns and villages they are unbearable," because there is only one doctor but "many matters to attend to."

Entering the room in silence, the doctor should greet the patient – "with great politeness and as calm a face as possible, both serious and tranquil" – and approach his bedside. He should use words and gestures appropriate to the patient; he should behave differently, in language and manner, with a man and a woman, with a scholar or a priest, a nun, a virgin, a cardinal or a duke, with a gentleman or a commoner, whether rich or poor.

The patient's room usually leaves a great deal to be desired; in fact, very rarely is care taken "of the patient's rooms and bed"; this neglect may harm the patient's health. Mercurio recounts good practices that he has seen in Spain, where the family decorate the invalid's room, keep it clean, and in summer adorn it with fronds and flowers. Not so in Italy, he complains, where the reverse happens. In the rooms of patients, unless they are noble and wealthy, there reigns confusion such "that it would make even angels melancholy." He therefore recommends cleanliness, tidiness, ornaments, leaves and flowers. Moreover, it would be good if the room also contained a small table with a white scented tablecloth on which the objects needed by the patient are arranged. In the morning, "it is good to open the windows for a quarter of an hour"; and when it is hot to sprinkle cool water mixed with vinegar. Paintings with sacred images should be hung on the walls. Also small birds should be kept in the room, because their song can cheer the patient; and the room should be warmed if it is winter.

Even the poor, who cannot afford many refinements, can nevertheless "sweep the room," keep it as clean as their poverty permits, "wash the bedpan," and "keep the patient's beaker clean"; especially because all this can be done without fear of dirtying their "precious garments," as would happen to nobles. In any case, "it is heart-rending to see a poor patient stricken by illness and covered with dirt."

However, "the good doctor" "constantly studies and endeavours to restore health." He has a constant desire to heal his patient, whom he does not abandon, but instead studies his illness. "He goes two and more times a day to visit him and to examine his spit, urine, and dung, and with much charity touches his wrist, and his flesh, even when there is some risk of infection, and approaches his bed with much familiarity."[11]

The doctor should come close to the patient to understand the causes of his illness from signs and symptoms. After examining the patient's excretions and excrement, taken his pulse and palpated his body, he orders the diet and medicaments. The latter will be prepared by apothecaries, and Mercurio recommends caution and precision. Only tested medicaments should be used, and they should not be too costly for poor patients. The doctor should also ensure that apothecaries do not use old ingredients or imprecise measures: “It is better to use a few well-known and tested remedies than accumulate a large amount of ones derived from books and tested blindly.” But however much the zeal of the doctor and the quality of the remedy might do everything possible to heal the patient, the latter should be aware that “the doctor cannot cure all diseases.”[12]

Analysis of the urine

At the time of Scipione-Girolamo Mercurio – but already in the age of Hippocrates – analysis of the urine was one of the main elements of the diagnosis; it immediately followed the patient’s description of his or her case history.

Analysis of the urine certainly had little to do with that of contemporary medicine. The doctor merely inspected the urine’s appearance and assayed its organoleptic characteristics in order to formulate a diagnosis. This observation was regarded as able to provide so much information about the disease that doctors sometimes did not consider it necessary to examine a patient if they could see his or her urine. The diagnosis in this case was made even in the patient’s absence – as we shall see, there were other ways to examine patients at a distance – merely by looking at the urine in a transparent glass cup, or what was known as a *matula*. The latter was a small glass vial, with a wide neck, clearly depicted in a series of paintings by Gerrit Dou, already mentioned above, and in many other paintings of the modern age on the same subject.

In fact, the visual inspection of urine, on which the diagnosis was largely based, also served – as recounted by anecdotes reported by Mercurio – to test not only the doctor’s skills but sometimes also his sense of humour. Besides being striking for their curiosity, these anecdotes also convey the everyday circumstances in which examinations were conducted.

Recounted in *Errori* is the story of an “astute” doctor of Desenzano who wanted to have people believe that he could recognize any disease solely by examining the patient’s urine. He had created a secret window which gave onto the entrance hall. His faithful maid received people bringing the urine of patients at the front door. The woman then asked a series of questions to find out the symptoms and course of the disease (while the doctor secretly listened). When the patient’s servant or relative entered the room in which the doctor was waiting, the latter with an “authoritative and serious air” took the urine and scrutinized it very carefully. He then repeated, in order, “what the foolish man had told the maid." Thus deceived, the man went away declaring astonishment at the doctor "who had recognized from the urine whether the patient had liquid or solid shit."[13]

On other occasions it was instead 'the people' who tested doctors simply by presenting, not the patient's urine, but that "of a donkey or horse. Sometimes presented was the urine of women rather than men, or of children rather than elderly patients, healthy persons rather than sick ones" just to see if the doctor would notice. Something similar, although more gracious as a joke, happened to Scipione-Girolamo Mercurio. Summoned to visit a sick lady, he wrote, some young women of the household "showed me a little Malvasia white wine in the glass instead of urine." But the young doctor was made suspicious by the smiling and grimacing of the girls as they handed him the glass, "and on not seeing that evident circle which urine usually makes at the top of the glass," nor the "sediment" that he had previously found in the patient's urine, he realized that he was the victim of a prank. In fact, the smell of wine arose from the glass; he sniffed it and saw a blush come to the face of the girl who had proffered the sample. He then turned to the lady, "Madame, you are healed, this is the sign, and raising the glass to his lips, he drank the Malvasia."

The joke is recounted with humour, and in fact Mercurio calls it "charming." However, he stresses, such things should not be done, because if the doctor is your friend and worthy of your trust, you should not deceive him; and if you do not trust your doctor, you should find another one. As for the nonsense recounted "in Italy, similar deceptions have persuaded us that even a woman's pregnancy can be known from her urine ...."[14]

Popular errors. Italy, France, England

Mercurio's description of medical practice, together with his definition of the figure of the doctor in the society of his time, is certainly not isolated testimony. Such information is provided by a work on 'popular errors in medicine' which was part of a literary genre: Mercurio, as said, considered himself a follower of Laurent Joubert, who had written his *Erreurs* in France two decades before Mercurio's *Errori*. A similar work was produced at the end of the seventeenth century by the Englishman James Primerose, whose *Popular errours* were written in Latin and translated into English, and then into French in 1689.[15]

These and similar works on 'popular errors' came to constitute a particular medical literary genre.[16] They had various features in common: mainly a description of behaviour by 'the people' deemed to be wrong, together with a more or less explicit attempt to improve it. This was to be achieved through assumption of authority by the doctor, and more precise definition of his professional role. Another feature is that these works were generally written in vernacular language (except for Primerose's, which will be discussed shortly) by doctors who actually practised medicine. This means that information derived from observation of behaviours common in society was criticized and corrected by the doctor, and then returned to the reading public. The latter was certainly not the general populace, but it nevertheless represented a section of society much larger than the small group of aristocrats and clergymen able to read Latin. However, the authors were practising doctors who delivered care in the everyday reality of disease and suffering. They testify to their concrete actions far more than they themselves, or their more learned colleagues, did in theoretical works? The writings on popular errors devoted most space to the patient.

Joubert, chancellor of the faculty of medicine at Montpellier, dedicated his *Erreurs* to Margaret of Navarre. In the preface he announced a humanist project to restore the principles of medicine. These had often been betrayed by doctors themselves, but nevertheless only doctors could reinstate them. The book covers a wide range of topics, as did all the subsequent literary genre of 'errors'. Joubert devoted the introductory part – exactly as Mercurio would do – to medicine, doctors, and the doctor-patient relationship. He addressed the "free and studious reader." One of the declared purposes of the work was to be of help to young doctors "distressed" by not being respected and esteemed. According to Joubert, the lack of respect for the medical profession, and the slander to which it was subject, were injurious to the patient's health. Joubert first dwelled on the "excellence of medicine" (a topic on which the other texts of this genre would also insist). He then considered the characteristics of the good doctor – with especial emphasis on selflessness and dedication – and finally discussed relations with patients. Here Joubert had occasion to complain about their scant gratitude, or indeed lack of it.[17]

Perhaps because Joubert's text (of around two hundred and thirty pages) was a prototype, it was subject to criticism. It provoked controversy both because of its use of the vernacular – then certainly unusual in scholarly works – and because it dealt with medical issues to do with sexuality, again discussed in the vernacular. But despite such criticism and controversy, the book was enormously successful, with numerous translations and many imitations.[18]

James Primerose (or Primrose) resumed these themes in his *Popular Error*s in the mid-seventeenth century, when the situation had not changed greatly since the times of his predecessors. Known for having been an opponent of William Harvey, Primerose originally wrote his book in Latin (London, 1638; Amsterdam, 1639). The text was translated into English (London, 1651), and reprinted in Latin (Rotterdam, 1658); but it seems to have circulated mainly in the French edition of 1689. Primerose, like those who had preceded him, discussed *errors* in medicine, following the sequence of physiology, pathology and therapy; and like Joubert and Mercurio he began with discussion of medicine, the doctor, and the doctor-patient relationship.[19]

In his detailed analysis of competition, Primerose devoted several short chapters to all the categories of those who wanted to practise medicine in the stead of the doctor: primarily the servants of doctors and apothecaries. Then came priests, "doctors of theology," and "those women who dabble in medicine and surgery." Finally, there were the quacks with their secret antidotes. But, wrote Primrose, a good physician should not only have numerous remedies, nor rely on luck; rather, he must have much studied and practised medicine, gaining experience, knowledge, and method. If he did not have these qualities, it was difficult to have people believe that he possessed them.

The foreword to the French edition introduced the text as "the translation of an English book which deserves to be heeded by all nations because it destroys popular errors of medicine, whose smallest mistakes are so dangerous!" Thus Primrose, who had opposed Harvey's theory of the circulation of the blood, cited conflicts among doctors as one of the factors responsible for popular errors.[20]

How the doctor should behave: the *galatei*

In his *Errori*, Scipione-Girolamo Mercurio had more to say about doctors, and in particular about the kind of doctor that he wished to see exercise the profession. He sought to specify, describe, and improve the role and function of the doctor in society, and to define his duties, responsibilities, and behaviour. However, it must be said that, apart from a more personal interpretation of the doctor's role and contextualization of his function in the towns and regions of Italy where Mercurio practiced medicine, his proposals concerning the doctor's conduct in his relationship with the patient, as well as his advice to patients, were entirely in line with the instructions and reflections contained in the medical *galatei* that flourished in Europe from the sixteenth to the nineteenth century.

The *galatei* (ethical manuals often of booklet size) were published for the primary purpose of proposing codes of behaviour deemed necessary for definition of the modern medical profession, of the physician who entered the profession upon obtaining a university degree.[21] Two or three centuries after their publication, the *galatei* gave early testimony of the values and 'qualities' that would influence the medical profession. In fact, through academic training and example, their teachings became part of the social definition of the modern figure of the doctor.

Obviously prescriptive texts, they accompanied the genesis of the medical profession in the modern age. Though not devoid of information about the everyday reality of medical practice, they especially depicted the role of the doctor and medicine in *ancien régime* society, and prefigured a codified relationship between doctor and patient. To summarize, a first group of instructions in the *galatei* always defended the legitimacy and prestige of medicine (not unlike the *Errori-Erreurs-Errors*) and the action of the doctor. They protected the doctor's actions against slander and criticism. Another group of instructions was intended to establish the doctor as absolutely the most competent caregiver and the only therapist worthy of trust and respect. Much was said against every kind of charlatanism. Finally, they described the qualities that a good doctor must possess, and how he should behave in the exercise of his profession, but also in his private and social life, so that his behaviour would not give rise to criticisms and rumours. The appendices to these recommendations often contained instructions and advice also on how the patient should behave.

Now examined are the 'qualities' of the doctor and the patient as defined by three works published over little more than two centuries in Northern Italy: *I doveri del medico e del malato* by Leonardo Botallo (1530-1587); *Li cento aforismi medico-politici* by Alessandro Knips Macoppe (1662-1744); and *Galateo dei medici* by Giuseppe Pasta (1791).[22]

The shared intent of the three works was to defend the dignity of medicine and the doctor against slurs and slanders; but they first required doctors themselves to be competent in their work. Necessary to this end was rigour in study and breadth of training, not just medical. Doctors were also required to be dignified in their habits and behaviour, polite and decorous in their attire, and they should also carefully groom their appearance. Finally, doctors had to possess the capacity to relate to the patient that was termed 'political'.

Whilst Botallo and Pasta described a virtuous, learned, and highly moral doctor, Knips Macoppe emphasised the opportunities for career, power, wealth, and status offered by the profession. Thus, precepts not unlike those propounded by the other two authors of *galatei* alternated in Knips Macoppe with invitations to be shrewd and even hypocritical.

For the Piedmontese Leonardo Botallo, the good doctor must be a man leading an upright life devoted to study.[23] However, his "diligence" required other qualities if he was to be "granted trust and gratitude by patients and their attendants." The "wise, honest and expert doctor who does not seek easy popularity" must endeavour to be "loyal with words and actions," combining "cordiality and discretion" in his demeanour. Also the manner in which the doctor presented himself had a good influence on the patient (as already suggested by Hippocrates, recalled Boltallo). Consequently, he should attend to his "posture, speech, appearance, clothes, haircut, nails, and body odour" (in this last case, Boltallo recommended a light perfume), as well as to his face, hands, and hair. The good doctor should ask about not only the patient's symptoms but also those of the persons close to him or her. In fact, the patient must "describe past and present symptoms that may contribute in some way to identifying the disease." It was well known, however, that the patient sometimes wanted to conceal "the true cause of the illness" from the doctor.

The doctor must always demonstrate wisdom, humanity, and moderation. He should show concern for the poor, who "do not have money to pay the doctor for an examination, nor do they have a servant or a family member to explain what is the matter to the doctor." He should be indulgent and not severe with the patient, who may sometimes be "capricious or intolerant": "affability combined with pity is a wonderful medicine!"

Finally, as in the other *galatei*, Botallo spoke of those around the patient: family members and "attendants." These were not always cooperative and obedient; instead they were ready to suggest diagnosis and treatment: "Therefore, attendants, friends, relatives of the sick person, or yourself the patient should cease discussing medicine with doctors when you find yourself having to do with this art ...." Also for Botallo the main ingredient of the doctor-patient relationship was trust: "Choose the doctor well and trust him."[24]

In the mid-sixteenth century there began to take shape the features of the medical profession in terms of appropriate training, areas of competence and action, and 'qualities'. Features similar to those described by Leonardo Botallo are also to be found in the writings of Laurent Joubert and Girolamo-Scipione Mercurio, who belonged to the same historical period.

Moving forward to the eighteenth century, the *galatei* exhibited the now almost complete definition of the medical profession adumbrated two centuries earlier, but they also referred to problems not yet fully resolved. Among the latter was that of competition by other therapists. Moreover, the two nineteenth-century *galatei* now considered highlight the complexity of the figure of the eighteenth-century doctor, and the different ways in which it was interpreted.

Alessandro Knips Macoppe, with his *Aforismi* – first published in Latin – was very much a doctor of his time; but he was also ahead of his time in his unscrupulousness. He proposed a code of ethics aimed at consolidating the scientific and social dignity and credibility of the doctor and medicine among the sick and their families and within society. To do so he used wisdom, but also guile that bordered on cynicism.[25] Besides requiring the doctor to possess broad theoretical preparation, Knips Macoppe argued that he must be attentive to advances in science and to debates among scientists. He should be correct in his relations with both colleagues and novices, and with travelling foreigners (Padua, his city, was an important university centre). Although convinced of the usefulness of good manners and skill in argument, the doctor should be aware that "the sick cannot be healed with words, but only with the correct application of medicaments."[26]

Knips Macoppe's behavioural prescriptions can be summarized as prudence and moderation in things both large and small. The doctor must know how to wait for the disease to evolve and to see the effect of the drugs; he must refrain from making "confident predictions"; he should not be too talkative or too silent. Knips Macoppe recommended "let there reign upon your face imperturbable tranquillity towards the patient." The physician should not prescribe expensive drugs in order to enrich the apothecary. The conduct of the doctor "should not offer opportunities for sarcasm, dispute or threat by patients and their families." He should show a "decent simplicity of ornaments accompanied by a pleasant and affable demeanour."

In other passages, Knips Macoppe showed himself an opportunist by advocating hypocritical behaviour: "When the art brings benefits and the healing is certain, behave in cheerful manner; but weep when everything conspires to predict death, for tears will earn you much." He likewise advised doctors to avoid hypochondriacs, as well as lawsuits and treatment of the incurable. He suggested being beneficent with the poor, so as "to obtain a good reputation." To obtain a good reputation it was also advisable to practise in hospitals; but if a doctor aspired to wealth, "he should detest the practical exercise [of medicine] bound to a public annual salary in villages or small country towns, which are inexhaustible sources of sorrow and drudgery."[27]

Around fifty years after Knips Macoppe, of different tone is the *Galateo* by Giuseppe Pasta, a doctor who had long experience also in the service of the poor. Pasta insisted on the need for the "sublime studies and sublime qualities" of the doctor, who besides medicine must have good knowledge of "the world" and the diversity and complexity of people.[28] For Pasta, the deep-lying motivations for the proper practice of medicine were very different from those of Knips Macoppe, although he gave many similar instructions as regards the doctor's behaviour, including attention to his appearance. His recommendations as regards knowledge, skills, and duties were not very different from those of the texts examined previously. Among the doctor's qualities he stressed the "moral virtues," the ability to be "modest, secret, charitable, prudent," and to give "sweet relief to those who suffer." Also Pasta sought to defend the dignity of the doctor; but he never suggested opportunistic behaviour to acquire good repute. The good doctor must never "flatter the vain" or "betray the sick." Uninterested in the wealth resulting from a large or prestigious clientele, Pasta wrote that "it is better to have a few patients in one's care than several; it is better to treat well than to treat many." He differed markedly from Knips Macoppe when he declared that "for the heart of an honourable doctor no patient must seem unworthy. The poor and the rich, the powerful and the helpless have equal right to the heart of such a doctor." For Pasta, in fact, even the "incurable" were entitled to the doctor's care and dedication; and although the patient might sometimes be "insolent, ungrateful, disbelieving, ignorant, unruly," the doctor must always patient, and if necessary "deftly accommodate the desires of the invalid." Like the other authors, Pasta invited doctors to use information from "attendants," but at the same time to impede their "conceited intrusion."[29]

The doctor – as also Scipone-Girolamo Mercurio had written – must also be "political," by which he meant that the doctor must be able to manage information, relationships and communication. Indeed, "it does not suffice that he treat with solicitude, safety and pleasantness; he should also do it politically." Whatever the doctor had to communicate, he should not say it discourteously; and he must never "frighten the patient." As regards examinations, to be noted is that Pasta advised the doctor to keep a "diary" on patients.[30]

Medical consultation by letter

The testimony consisting of the extant correspondence between doctors and patients furnishes an abundance of first-hand information on the therapeutic relationship and its actors; although it inevitably describes a practice that was restricted to a small group of people. This kind of therapeutic practice seems to have been much more widespread than thought. But it should be borne in mind that some of the doctors whose ideas were reported above did not consider consultation by letter a good way to relate with the sick.

In recent years, studies on the social history of medicine, doctors and patients, diseases and treatments have devoted particular attention to this type of handwritten testimony (sometimes published). Medical consultation by letter highlights a direct exchange, if not always between doctor and patient, then certainly between a witness to the patient's condition and the distant doctor. We therefore have descriptions followed by opinions and advice. Although the correspondence sometimes adopts a highly standardized format, it is always rich in detail.[31]

One of the most celebrated doctors to have treated patients at a distance by using his pen "to negate absence and remoteness"[32] was Auguste Samuel Tissot, whose case is informative of the kinds of patient that sought advice from a medical luminary by correspondence.

In general, until the end of the eighteenth century, the majority of correspondents belonged to the uppermost echelon of society: aristocrats, clergy, army officers, and merchants. However, there was no lack of middle-class patients, and to a minimal extent even lower-class ones[33]– although Tissot's estimate of the clientele 'by letter' is certainly not generalizable. Epistolary consultation was a paid medical service, which in late eighteenth-century France cost the equivalent of sixty days of a low-skilled worker's labour. In France, the service was used by "the aristocracy and the urban bourgeoisie, which probably accounted for the majority of requests for written consultation in the last years of the eighteenth century."[34]

Epistolary contact with a doctor was possible not only for those able to pay but also to those who could write with fluency and were therefore scholars or the literate. Usually treated by letter were sufferers of chronic diseases; excluded were degenerative diseases like those often afflicting children. But the remote consultant was also contacted by patients dissatisfied with the treatment received from the doctor of their village, as well as by the discouraged sick who had consulted several doctors and received contradictory diagnoses.[35] Epistolary consultation was also requested by persons who had to conceal their illnesses. In these cases, the consultant received anonymous letters delivered by an intermediary. Only after a series of exchanges did the patient sometimes reveal his or her identity, reassured by the trust that the doctor had been able to develop. These were generally persons suffering from sexual disorders – such as impotence – which entailed respect for modesty and privacy.

The letters testify that the correspondence between the patient and the remote doctor was not the only relationship that the patient would have with a medical practitioner. In fact, patients were usually also treated by their village doctor, or by a personal doctor if they lived in a city. They might also be approached by unqualified quacks, as well as pharmacists and herbal friars. The relationship with a renowned, but distant, doctor was therefore an additional one, which did not replace the normal relationship with the patient's doctor and with other practitioners available on the therapeutic market.

It is not possible here to describe in detail the large body of research on epistolary consultation. Considered in what follows, therefore, are some particularly important aspects, the first of them being the 'direct' testimony of patients.

Treatment by letter was also possible because, after the doctor had inspected the patient's urine and taken his or her pulse, a medical examination was mostly based on description of the patient's symptoms and case history. But the visit usually took place on a personal basis, and the patient's description was by word of mouth. Whence derives the exceptionality of having the patient's written testimony with the description of his or her illness. Moreover, it should be recalled that disease was conceived as an individual matter and therefore as bound up with the particular patient's physical characteristics and "balance of humours."

However, the description of the patient's disease, symptoms, and suffering was not always direct. We have seen that numerous others were routinely present at the scene of the doctor-patient relationship, and also in the case of an epistolary consultation. Often, therefore, it might be a family member, a friend, an 'attendant', or even a therapist – the local doctor or surgeon – who took pen and paper and wrote a letter. It should be noted that this type of correspondence was also used by a large percentage of women; indeed, in some cases female patients amounted to almost fifty percent of the correspondents. These were therefore women able to describe their ailments, sometimes directly.[36]

We also know from this correspondence that whether the patients were men or women, they were not always as 'obedient' as the doctors – and the *galatei* – wanted. Instead, they tended to discuss the diagnosis and treatment, to interpret the doctor's opinion as they wished, and to negotiate the therapy proposed.

Women patients

'Medicine of women and medicine for women' from the modern age to the nineteenth century concerned, on the one hand, different forms of medical-philosophical thought about the female body, and on the other, the exercise of diverse therapeutic practices. Rarely, in fact, was there a correspondence in those centuries between what doctors thought and wrote and the medical care of women, who in most cases were treated by women. Only gradually, from the sixteenth century onwards, did women become the subjects of medical texts, and they were generally treated with orally transmitted folk remedies.

For centuries, in fact, medical thought and study centred on the adult male. Areas of medical knowledge concerning women were defined by default. The main difference between men and women established by medical thought – with enormous social consequences – was the capacity of women to breed. Learned medicine from classical Greece until at least the sixteenth century –but in many cases for a long time thereafter – did not depart from this model. Also the analysis of celebrated lawsuits and case studies shows that this form of traditional thought, highly prejudicial towards women, continued to be strongly influential in the medicine and societies of the modern age.[37]

While men had written medical texts for women – *de morbis mulierum* – 'medicine for women' was mainly, or almost entirely, practised by women who furnished care, listened, and passed their knowledge on to others. Obstetricians not only attended to women in pregnancy, childbirth, and puerperium; they were also concerned with women's sexuality, beauty, love-lives, and diseases. Since antiquity until the recent past, the occupation of midwife-obstetrician had merged with that of healer and therapist of the "ills" of the female body. Only with professionalization of the profession of midwife, especially after the eighteenth-century reforms, did the tasks of the obstetrician centre almost exclusively on treatment of problems related to reproduction.

From the sixteenth century onwards, therefore, the medical literature on women's diseases began to change in nature, especially because of the closer attention paid the female body, which was still considered fragile and 'naturally' sick. Also the medical texts now distributed in printed form testify to the greater concern of doctors for women. But, with a few exceptions among the highest social class, it was still rare for women to be treated by a doctor.

Discussion of problems concerning the reproductive function – menstruation, pregnancy, childbirth, breastfeeding, and puerperium – filled the pages of medical texts on female diseases. This situation changed (though certainly not rapidly) because of two developments. The first was the extension, theoretical and practical, of the conception of female disease to encompass a broader and more complex array of pathologies extending beyond the strictly sexual and reproductive sphere. The second was the ever more frequent presence of the doctor at the sick (and pregnant) woman's bedside.[38]

In France, Diderot-D'Alembert's *Encyclopédie* emphasised the image of women as perpetually and 'naturally' plagued by physical and 'moral' ('mental' one would say today) disorders due to their sexuality.[39]

Complications in menstruation, pregnancy, and childbirth were among the topics most commonly discussed when doctors concerned themselves with women's diseases. Female sexuality, however, was now deemed responsible (especially from the eighteenth century onwards) also for particular mental illnesses of women, like melancholy, but especially hysteria.

Recent studies on female patients in the English-speaking countries – early modern Britain – have examined, besides treatises, also handwritten sources: casebooks, letters, and doctors' diaries.[40] Analysis of these manuscript materials evidences the specificity of the medical treatment given to women by male doctors. Even in the case of problems now considered common to both sexes, the evidence does not support the idea of a one-sex model[41]. In its relationship with the patient, medical practice was highly sexed in the diagnosis and treatment of all diseases. The reproductive function of the female body influenced diseases and therapies in medical thought.[42]

In everyday practice, not many women of modest means could use qualified doctors. Some of them, however, were able – as seen – to do so through epistolary consultation.

With progress in scientific obstetrics, and advances in medical examination techniques, a major change came about in the relationship between doctors and female patients. It was for this reason that Alexander Knips Macoppe recommended prudence, propriety, and self-control when dealing with a female patient:

> When assisting women I enjoin you to be of extreme politeness. Should the circumstances require you to touch the bosom, the lower abdomen, or explore the most hidden parts, constantly act, or at least pretend to act, as if you were as insensitive as marble or ice. A foul stain shall be upon your name if by lubricity of hand, or wickedness of intent, or even with words, you violate the sacrosanct laws of modesty.[43]

We are now in the late eighteenth century, when it became less surprising to find a doctor present at the bedside of a sick woman, or a male obstetrician at that of a woman in labour, and when medical gynaecology had begun to spread. It was not long since a booklet entitled *De l'indecence aux hommes d'accoucher les femmes* had been issued.[44]

It is not the intention here to dwell on the 'obstetric revolution' of the eighteenth century, but merely to emphasise a particular aspect of it: the introduction of 'exploration' of intimate female parts by male hands. In 1791 Vincenzo Malacarne published *La esplorazione proposta come fondamento dell'arte ostetricia.*[45] The book established the need for gynaecological examination, in particular to determine a woman's state of virginity or pregnancy. To be sure, wrote Malacarne, the (general) doctor often "for excellence of education, and because of the principles of civility and decency, and disposed to respect modesty" prefers an obstetrician to examine a woman in her "private parts," "shameful parts," the *pudenda* of Latin.[46] But something had changed profoundly in the relationship between the woman patient and the doctor. The iconography of the medical texts of the eighteenth century is eloquent: it depicts the doctor approaching the woman's body and touching it, even beneath her clothes.

Reconciliation with the sense of decency was slow and contentious; but there gradually developed a relationship of respect and trust between the male doctor and the female patient. Not rare are testimonies showing that doctors were generally "sympathetic and responsive to the needs of their female clientele."[47]

Child patients

The English physician Walter Harris wrote that doctors began to treat small children very slowly and "with great disgust" at the end of the seventeenth century.[48] A century before, Girolamo Mercurio in his *De morbis puerorum* had asked whether sick children should be treated by a doctor[49]. In his view, given the exposure to disease of "that tender age," it was "reasonable" that "the defeat of diseases and dangers should be entrusted to doctors." He concluded that sick children required the attention of a doctor because a growing human being "is needful of help from others," and children should be "treated with medicines and freed from illnesses" by doctors, who with "prudence and skill" should care for them as well. Mercurio wrote this because at that time, and for long thereafter, doctors did not generally treat children (unless they were children of courtiers).[50]

Whilst in the first of his works Scipio-Girolamo Mercurio had instructed midwives-obstetricians on what they should do with sick children "when there is no doctor,"[51] in *Errori popolari*, he considered it a grave error "rampant throughout Italy, almost a madness, [to believe] that doctors are superfluous to children." Mercurio identified two reasons for the lack of interest among doctors in child care, although they should be placed together with his statement concerning the widespread belief that it was nature which healed (or otherwise, one should add) sick children.

A child, especially if small, could not describe his or her illness. Moreover, children, particularly if breast-fed, could not be given the same medications and treatments that doctors prescribed for adults. But, in fact, there was no lack of medical practitioners who adjusted to the care of small children by using methods able "to put into their bodies the medicines that they are unable to take."[52]

Although the doctors of the Renaissance who dealt *de morbis puerorum* – like those who followed them – used the term *pueri* in their writings in Latin, they were in fact often referring to children unable to speak, and therefore *infantes*: infants who could not speak, or older ones who, although beginning to talk, were certainly not able to describe their symptoms.

Then, in 1689 Walter Harris, on starting to write his book, and following the advice of Thomas Sydenham, made great efforts to furnish his cures and services to sick children in need of medical care. However, on considering the medical thought on the subject, Harris realized that, although it was not a complete desert, the path was by no means an easy one. The development of medicine for children, wrote Harris, would meet with the favour not only of families who needed heirs but also of people of every condition "who naturally love their children" but are unable to care for their health, just as they are unable to care for their own. Harris's intention, therefore, was that his work should give impetus to the advancement of this branch of medicine. As regards the difficulty of diagnosing childhood diseases, he did not deny the problem; but, besides indicating possible solutions, he lamented the lack of dedication among doctors. He insinuated that doctors who complained of the difficulty of treating sick children because they could not talk, used this difficulty to conceal their ignorance, their errors, and their reluctance to engage with this branch of medicine.

Of course, knowledge about the diseases of children could not be deduced from what they recounted, nor from taking their pulse or inspecting their urine, because these methods were less informative with children than with adults. However, a great deal of information could be obtained from the women of the household attending to the sick child, as well as from the doctor's questions to family members.

Further information was forthcoming from examination of the sick child, and from inspection of his or her stools. The doctor began by looking in the child's mouth to see if the gums were swollen and whitish due to teething. He then saw if the lower abdomen was bloated or had other swellings; and if the child had spots, pimples, rashes on his or her body, and yellow or instead reddened skin. After these tests, wrote Harris, the doctor must proceed with theory and reflection, no longer with practice.[53]

This concept was often repeated by later authors throughout the nineteenth century, with the addition of the invitation to consider that, also in the case of mentally ill adults, the doctor certainly could not rely on the words of the patient.

There are no explicit declarations on the importance that doctors should treat children in the works of the Swede Nils Rosen von Rosenstein (1706-1773), whom many historians of medicine consider to be the father of modern paediatrics. There is, however, evidence that he himself frequently treated sick children, of whom he constantly spoke in his treatise on children's diseases.[54]

Whilst in the seventeenth century the Londoner Harris had recommended first questioning the "onlookers" when examining a child and then consider the theory, almost a century later George Armstrong, also in London, wanted paediatric medicine to start with practice and only later turn to theory. The hospital (or dispensary) for poor children thus became a place of study and experimentation – as it was in Milan during the same period for Pietro Moscati and Gian Battista Palletta – but above all a place of charity, assistance and care.[55]

To be noted is that when Armstrong published his *An Account of the Diseases most Incident to Children* (1767), treatment of child patients was not considered a dignified professional practice for a doctor. Furthemore, Armstrong had established the Dispensary for the Infant Poor, a day clinic for sick children, because he believed that it was harmful to separate children from their families for treatment in hospital[56]. It appears from his writings that Armstrong's concern was less to advance science than to devote himself to social work and philanthropy; we know from his biography that his commitment was also financial.

Personages like Rosenstein, Armstrong, and also the Italians Moscati and Palletta – as well as Blankaart in Holland and Harris in London in the previous century – were still isolated cases of doctors who committed themselves to the treatment of children. They were driven to do so by an immediately apparent social problem – poor and sick infants – and by a professional ambition to expand the range of medical care to include children, thereby challenging the resistance of their own professional group. Hence they were exceptions and precursors. As evident upon reading the *Encyclopédie* of those years, the call for doctors to care for sick children still went largely unheeded.

> It is therefore very important for humankind – whose conservation is entrusted to doctors – that the latter should assume responsibility for the defence of children against everything that assails their lives; they should apply themselves to studying the evils to which children are subject; to discovering the signs with which the nature of these evils can be identified, and to foreseeing their consequences; they should seek the means and precautions with which they can be avoided; finally, they should find the remedies with which to free them [from disease].[57]

The entry *Maladies des enfants* thus evidenced that the situation was beginning to change.

The patient, the doctor, and the others

> The sick who are rich or affluent form a small minority. At their disposal are physicians in the city, and surgeons in the countryside. Use of their services testifies to a certain economic level and a certain social and cultural rank. Examinations, consultations, and remedies are costly. They require quite considerable income, even if the practitioner does not ask for payment immediately but instead in instalments. Moreover, the medical profession, with displeasure if not with anger, faces competition by apothecaries and itinerant quacks. Therefore, preferential recourse to a member of the medical profession testifies to a written – to wit, learned – culture that is not necessarily the appanage of all.[58]

Some aspects of the doctor-patient relationship have not been considered thus far. Among them is the work of *condotte mediche*, that is, panel doctors paid by the community to care for the poor, an exemplary Italian practice since the Renaissance and which Giuseppe Pasta mentions.[59]

Another important topic is that of doctors' fees and payment for medical services; a matter considered by several studies, which have shown the complexity of the *ancien régime* reality in this regard as well.[60]

All the authors considered here said that the doctor must be paid. But they were all wary of payments made according to a contract, the so-called 'healing pact', on which interesting hypotheses have been put forward, though sometimes subsequently contradicted by the historiographical debate.[61] The doctors considered in this study regarded such pacts as worthy only of charlatans, not of doctors.[62] Knips Macoppe was explicit on the matter when he urged doctors "not to stipulate payment for care of the sick: only rogues and charlatans engage in such unseemly negotiation."

To be reiterated is that other figures besides the doctor offered their services and remedies to the sick. Not only was it rare for the doctor to be the sole therapist to whom a sick person, or his family, resorted, but, as the sources repeatedly report, other persons were involved in the relation, or on the scene when the main therapeutic actors were the doctor and the patient. Present in the patient's room, as well as in the epistolary correspondence, were servants, messengers, advisors, friends and family members (especially women) who gave their opinions, interfered, and sometimes wrote in the stead of the patient. Nor has this study considered (because the topic falls outside its scope) recourse to prayer and religion, which were nevertheless of significant importance. It also seems from the sources that the search for therapeutic relief seems to have moved in various directions and also consultations were often more than one in number, the 'plural interview.'[63]

By the late eighteenth and early nineteenth century, the figure of the doctor had begun to appear with increasing frequency on the everyday scene of illness; as also testified by the visual sources. An Italian ex-voto (i.e. a votive tablet donated "for grace received") of the early nineteenth century depicts two patients, a man and a woman, in a double bed. It then portrays a kneeling young girl pointing to the Madonna (painted in the upper left of the tablet), a priest, and another man standing at the foot of the bed; and then, to one side, a person who is clearly recognizable – because of his hat, clothes and demeanour – as the doctor. Affixed to the wall behind the headboard are a crucifix, a holy water stoup, and a sacred image.

The doctor is physically beside the sick man and woman, in a dwelling perhaps not poor, but not rich either. Recourse to his assistance and his cures was becoming as customary as the appeal to religion for help. The doctor now competed with the sacred. This is perhaps the first image of this type in the iconographic genre.[64]

An image of another kind, and which this time testifies to the changed relationship between the female patient and the doctor is contained in a late eighteenth-century Italian manual on obstetrics.[65] It shows a woman lying on a bed while a doctor examines what were still called the *pudenda*, the "private parts." The woman is giving birth to a breech baby. She is richly dressed, with the skirt of her gown raised, and bloomers covering her knees. A foot of the foetus is emerging from between her legs while the doctor fumbles, keeping his head turned to one side. The 'exploration' proposed as the foundation of the obstetric art allows the doctor to touch the woman's body in its most intimate parts without offending her modesty. The 'artifice of the representation' enables us to see the interior of the uterus; but perhaps we can consider also an 'artifice' the man's eighteenth-century clothing – with his sleeves rolled up – and his wig. Another picture, this time French and less harsh, illustrates a gynaecological examination, external, with the woman fully clothed, and her skirt lifted just enough for the doctor to slip his hands under it.[66] The doctor has his knees bent and, like his Italian colleague, his head is turned aside to avert his gaze from the patient. On the women's faces depicted in these images are expressions of modesty and shame (in the case of childbirth, a grimace of pain). Also the doctor's head turned to the 'viewer' (the reader of the book containing the image), is an artifice of visual representation, or when possible, a behavioural device enabling the doctor to approach the woman's body.

Doctors do not only take the pulse and inspect the urine of patients, or treat them by letter if they are literate and affluent. The relationship is a close one; distance has been reduced also physically. The doctor has well introjected what his role requires.

Finally, in another image, a doctor with a hat on his head appears next to a sick child in an early nineteenth-century French print entitled *Le médecin de campagne*.[67] The many details of the scene well represent information to be found in an entirely different type of historical document. The child, only a few years old, is in the arms of two women (the women of the household). Sitting on the knees of one woman, he rests his head on the chest of the other. Beside the doctor and the two women a little girl watches, while behind them a servant adjusts the curtains on a four-poster bed: these are the people at home, the assistants. The doctor, depicted in profile, is fully dressed from the hat on his head to the spurs on his boots, his ruffle sprouting from between the lapels of his jacket. With a bended arm he holds his cloak fallen from his shoulders (he has not even taken off his cloak for the examination). He raises the child's arm with his left hand, and palpates him with the right one. Next to the doctor is his dog. Beyond the front gate we see the doctor's horse waiting for him.

Early childhood care has thus passed from the women of the household to the doctor. The doctor now also treats sick children.

The scene and the plot change, but the characters do not: there are doctors and patients (and always attendants). As at the time of Hippocrates, doctors must still address the issues outlined in the first of the *Aphorisms*:

> Life is short, and Art long; the opportune moment is fleeting; the practice is uncertain, and the decision is difficult. The physician must think not only about what to do but also about the patient, the attendants, and external factors.[68]

Notes

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2 Gerrit Dou, *Visit of the Physician*, Musée des Beaux-Arts, Angers, France; Jean Edmé Pigal, *The Rich Doctor and the Poor Patient*, Bibliothèque des Arts Décoratifs, Paris; Pietro Longhi, *La dama ammalata,* Ca' Rezzonico, Venezia, Italia; Gideon Harvey, *Ars curandi morbos expectatione* (Amsterdam: --, 1695).

3 Girolamo (Scipione) Mercurio, *Degli Errori popolari d'Italia libri sette* (Venezia: Ciotti, 1603).

4 Laurent Joubert, *Erreurs populaires et propos vulgaires touchant la médicine et le régime de santé* (Bordeaux: Millanges, 1579).

5 Mercurio, 1603, 43, 192, 184, 1, 322.

6 Joubert, 1579, 39-40.

7 Mercurio, 1603, 221, 189, 248

8 Mercurio, 1603, 182, 244-246.

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11 Mercurio, 1603, 239, 108-9, 214-15, 217, 83.

12 Mercurio, 1603, 155.

13 Mercurio, 1603, 174.

14 Mercurio, 1603, 174-75.

15 James Primerose (Primrose), *Popular Errours or the Errours of People in Physicke, First Written in Latine…Translated into English by Robert Wittie* (London); James Primerose, *Traité de Primerose sur les erreurs vulgaires de la médicine* (Lyon: Jean Certe, 1689).

16 See Joël Coste, *La littérature des «Erreurs Polulaires». Une ethnographie médicale à l'époque moderne* (Paris: Champion, 2002); Claudia Pancino, *"I medicamenti sono di tre sorti." Magia, scienza e religione ne «Gli errori popolari d'Italia» di Scipione Mercurio (1603)*, in Adriano Prosperi (ed), *Il piacere del testo. Saggi e studi per Albano Biondi* (Bulzoni: Roma, 2001), 385-421.

17 Joubert, 1579, 26.

18 Coste, 2002, 33, 26.

19 Coste, 2002, 56.

20 Coste, 2002, 56-57; Joubert, 1579, 89.

21 See Inge Botteri, *Galateo e galatei. La creanza e l’instituzione della società nella trattatistica italiana tra antico regime e stato liberale* (Roma: Bulzoni, 1999); Massimo Baldini, Antonello Malavasi (eds), *I galatei del medico e del paziente. Da Ippocrate al Codice Deontologico* (Roma: Viviani, 2008); Jean Pierre Goubert, *Malades et médecins à Saint-Malo à la veille de la Révolution* (Rennes: Presses Universitaires de Rennes, 2013); Maria Conforti, Andrea Carlino, Antonio Clericuzio (eds), *Interpretare e curare. Medicina e salute nel Rinascimento* (Roma: Carocci, 2013); Giuseppe Olmi, Claudia Pancino, *Anatome. Sezione, scomposizione, raffigurazione del corpo nell’età moderna* (Bologna: Bononia University Press, 2012); Luc Bervilet, Maria Pia Donato (eds), *Normale/patologico, sano/malato dal medioevo al contemporaneo, Quaderni Storici,* 136 (2011), 3-184; Giuseppe Olmi, *Medici e medicina nel Rinascimento*, in *Anatomia depicta ... trascrizione, traduzione e commenti*, (Roma: Istituto della Enciclopedia Italiana, 2010), 87-100; *Philippe Hecketsweiler, Histoire de la médecine: des malades, des médecins, des soins et de l’éthique biomédicale* (Paris: Ellipses, 2010); David Gentilcore, *Medical Charlatanism in Early Modern Italy* (Oxford: Oxford University Press, 2006); Jacques Léonard, *La France médicale au XIX^{e} siècle* (Paris: Gallimard, 1978).

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23 Botallo, 1981, 55.

24 Botallo, 1981, 122.

25 Baldini-Malavasi, 2008, 37.

26 Knips Macoppe, 2008, 44.

27 Knips Macoppe, 2008, 52-62.

28 Pasta, 2008, 78-79.

29 Pasta, 2008, 80-82.

30 Pasta, 2008, 88.

31 Goubert, 2013, 123. See Robert Weston, *Medical Consulting by Letter in France (1665-1789)* (Farnham: Ashgate, 2013); Joël Coste, *Les écrits de la souffrance. La consultation médicale en France (1550-1825)* (Seyssel: Champ Vallon, 2014); Lynda Payne, *With Words and Knives. Learning Medical Dispassion in Early Modern England* (Aldershot: Ashgate, 2007).

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un médecin du XVIII^{e} siècle: Samuel Auguste Tissot (Lausanne: Ed. BHMS, 2013), 52.

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35 Coste, 2002, 26.

36 Pilloud, 2013, 104.

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41 Churchill, 2012, 225-227.

42 Churchill, 2012.

43 Knips Macoppe, 2008, 67-68.

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59 See Donatella Bartolini, *Medici e comunità. Esempi dalla terraferma veneta dei secoli XVI e XVII* (Venezia: Deputazione, 2006).

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62 Macoppe, 2008, 67.

63 Coste, 2002, 23, 42.

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Chapter Four

Between law and profession: the origins of informed consent (1840-1900)

Emmanuel Betta

Informed consent to medical treatment is a matter much discussed in the bioethical, clinical, and international legal literature. The debate concerns its nature both as a formal act resulting from a culture of the individual's co-participation, rights and decision-making autonomy, and as a concrete experience and practice in a multicultural context.[1] The importance of informed consent has also been historically expressed through progressive legal formalization. After its first appearance in US medicine during mid-nineteenth century, the notion acquired concrete definition through a series of decisive acts: the Nuremberg Code of 1947; the Declaration of Helsinki of the World Medical Association of 1964; the Convention on Human Rights and Biomedicine of 1997; and the subsequent Charter of Fundamental Rights of the European Union of 2009. These were successive stages in the ever closer legal attention paid to the issue of rights in medicine.

Historiographical research on informed consent has focused on the second half of the twentieth century, after the drafting in 1947 of the so-called Nuremberg Code. On that occasion, when the American military tribunal sentenced the Nazi doctors responsible for the experiments conducted in the concentration camps, it established a set of principles regulating medical experimentation on human subjects. The voluntary consent of the latter became an absolutely essential requirement.[2] Research has considered the impact of this code in several Western countries in relation to diverse pathologies, and it has yielded some significant findings.[3] On the one hand, research has shown that the gradual abandonment of the Hippocratic principle of *primum non nocere* and the emergence of the theme of the patient's conscious consent to medical-healthcare practices in his/her regard results from the professionalization of US medicine which began in the second half of the nineteenth century. Secondly, historical studies have shown that discussion on the ethical limits of the doctor's therapeutic action, his/her responsibility towards the patient, and whether consent should be obtained from patients or their family members, also developed in the Francophone area in regard to the termination of pregnancy for therapeutic reasons.[4]

The issue of consent to medical treatment first arose in 1914, in the case of *Schloendorff v. The Society of New York Hospital*. The judge Benjamin Cardozo ruled that the patient must be an active party in the therapeutic treatment because all adult and healthy human beings have the right to determine what is done to their bodies. Consequently, an operation performed by the surgeon without the patient's consent constitutes an assault, except in cases of emergency where the patient is unconscious. However, the expression 'informed consent' made its first appearance in 1957, in *Salgo v. Leland Stanford Jr. University Board of Trustees*. The case concerned permanent paralysis of the lower limbs caused to a patient by an aortography. The California Supreme Court ruled that the doctor had a duty to furnish all information necessary "to form the basis of an intelligent consent by the patient to the proposed treatment."[5] This ruling marked abandonment of the idea that the doctor alone could decide how much and what information to give to the patient. This was replaced with the principle that the patient must have sufficient information with which to decide consciously about his/her medical treatment. Thereafter, the issue of the patient's informed and active consent to medical decisions increasingly asserted itself in the medical debate. In the early 1970s, self-determination in therapies began to be considered a human right requiring absolute protection.[6] From this point of view, the history of informed consent is considered to have been written mostly in the United States during the second half of the twentieth century: to the extent, indeed, that informed consent is considered "a modern American invention."[7]

However, whilst the emergence of the patient's explicit right to decide on his/her therapeutic treatment – as a product of the granting of the individual's right to self-determination – is a quite recent historical development, reflection on changes in the doctor/patient relationship, also in regard to decisions on therapy, has had long-period ramifications.[8] In the fourth volume of the *Laws*, Plato stated that the doctor should tell the patient and his family members about the diagnosis and the therapy, and then convince them of the goodness of his decision. Various passages in the *Corpus Hippocraticum* refer to the doctor's duty to do good for the patient and not to cause him harm. The doctor was consequently required to self-regulate his actions. He should not tell the patient the whole truth if this might undermine the latter's confidence in the doctor and the treatment, and hence his active participation in the therapy. In the Greek conception, however, the doctor and patient were united through *philia*: the friendship whereby their goals converged and an identity of interests was constructed so that confidence and trust in the doctor's action were the preconditions for the cure's efficacy.[9]

Various interpretations have been put forward in the discussion on the origins of the principle of free and informed consent in medical practice and research. Some studies have concluded that, before the last decades of the 1900s, medicine did not substantially address, nor recognize, the idea of sharing medical choices and decisions with the patient. In this regard, especially Jay Katz has argued that, for large part of history, the doctor/patient relationship was a silent one. According to Katz, doctors were silent because of their "unfamiliarity with and embarrassment over conversing with patients about medical ignorance and uncertainties that can so decisively affect choice of treatment."[10] The decision on treatment was therefore taken only by the doctor. Hence, according to Katz, before 1957 there was no consent because communication and consent were "obligations alien to medical thinking and practice."[11] A different interpretation is that of Martin Pernick, for whom "truth-telling and consent-seeking" were envisaged in American medicine even in earlier periods because they were considered able to produce beneficial effects on the patient's health.[12] Ruth R. Faden and Tom L. Beauchamp have proposed an interpretation midway between those of Katz and Pernick. They argue that the different interpretations concerning the existence of informed consent before 1957 were the products of different methodological approaches. Faden and Beauchamp agree that informed consent is a twentieth-century matter and maintain that history shows "how inadequately, and with what measure of hostility and insularity, problems of truthfulness, disclosure, and consent were framed and discussed prior to the twentieth century."[13]

However, although both interpretations restrict the history of informed consent to the twentieth century, they acknowledge the existence of traces of that history in earlier periods. Katz identifies the case of *Slater v. Baker and Stapleton* of 1767 as the beginning of the process by which legal definition was given to the doctor/patient relationship. On that occasion, an English court ruled that an experimental treatment of a broken arm was improper because the doctors had performed the operation against the patient's will. The doctor/patient relationship, however, was still marked by a paternalistic approach whereby doctors would share information with patients only to comfort and reassure them; not because the doctors recognized the patients' right to receive information about the treatment of their body and to participate actively in decisions about their health. In the age of the Enlightenment, the public dissemination of medical knowledge had been promoted in accordance with total trust in reason. Accordingly, in 1772 John Gregory, professor of medicine at the University of Edinburgh, advocated openness and honesty with patients, not, however, in recognition of their autonomy but once again within the beneficent-paternalistic paradigm. Likewise, Benjamin Rush, a revolutionary and one of the signers of the Declaration of Independence, recommended the sharing of medical information. But it should be shared on a hierarchical basis, so that the doctor did not have to respect the patient's decisions if they diverged from his own. Finally, in 1803 Thomas Percival, a doctor at the Manchester Infirmary, published his *Medical Ethics: A Code of Institutes and Precepts Adapted to the Professional Conduct of Physicians and Surgeons*, in which he explicitly addressed the issue of truthfulness between patient and doctor. Although Percival still essentially embraced the paternalistic view of the doctor-as-benefactor, he wrote that the patient's best interest was the doctor's prime concern. Consequently, if the truth was unpleasant or disturbing, it had to be withheld from the patient so as not to cause distress and undermine confidence in the doctor's action. Percival's book was nevertheless significant because it influenced the *First Code of Medical Ethics* issued by the American Medical Association in 1847. Several passages in that code were taken verbatim from Percival's book, including its recommendation of "beneficient deception." But the official introduction to the *Code* also emphasised that "veracity, so requisite in all the relations of life, is a jewel of inestimable value in medical description and narrative."[14]

Throughout history, the relationship between doctor and patient has exhibited features that allow a periodization whereby informed consent is a very recent result of the medical and legal discourse, and it is primarily rooted in English-speaking experience. This article investigates some of these features by considering how the doctor and the patient stood in relation to therapeutic decisions in the historical period that preceded the advent of informed consent. The inquiry will focus on the medical literature, which performed a twofold role: first, it was a means to communicate knowledge about practices, theories, and procedures to the medical community; second, it was an arena for construction of an authoritative and efficient image of medicine as biopolitical expertise decisive for governance of the body and health. The analysis will consist of systematic scrutiny of two journals: the *British Medical Journal* and the *Bulletin de l'Académie Nationale de Médecine de Paris*, both of which were the organs of national professional associations. A parallel analysis will examine the medical literature concerned with the ethical and professional constraints on the doctor's action in relation to the patient's wishes. The survey will trace the presence of the entry *consentement-consent* in these journals, investigating its semantics with reference to the doctor/patient relationship and decision-making in medical care. The survey will cover the time period ranging from the mid-nineteenth century to the threshold of the twentieth – a historical period which saw the birth of the clinic and the transition from 'bedside medicine' to 'hospital medicine' as the professionalization of medicine began.[15]

The guiding hypothesis of the analysis is that the legal perspective was a major component in construction of the idea of the patient's active participation in medical decision-making. This reference to the legal dimension, however, seems to have been made to protect not the patient but the doctor, who amid full-scale professionalization often had to act on the boundary between legality and illegality without formal protection from the law. This liminal situation was particularly evident in obstetrics and surgery: in these cases, from abortive to mutilative surgery, the doctor acted without the formal guarantee of a case-law precedent which would protect him against prosecution for abortion or assault. The patient's consent seems to have been defined with the purpose of ensuring the doctor's impunity. But recognition of the patient's capacity to furnish this minimum defensive guarantee for the doctor gradually gave rise to the notion that the patient was able to make a conscious and binding contribution to the medical decision.

In the specialized press, the term *consent* was employed in a composite semantic field covering a range of different matters. The term was most frequently used in relation to the legal legitimacy of a contract of matrimony, where the law required full capacity to understand the nature of that contract. Hence, consent mobilized the question of mental soundness, doing so initially with respect to two specific parties: minors and so-called 'lunatics'. The second most frequent use of the term *consent* concerned confirmation by other doctors or the entire medical community of the validity of procedures or practices proposed by an individual doctor. The term *consent* was often used in another sense as well: that of assent by the patient's relatives or friends to an autopsy, or the acceptance of gynaecological examinations by women in cases of alleged sexual assault.

Besides these meanings, however, the term *consent* was mostly related to medical choices and decisions. It concerned therapeutic choices by sane women, mental patients, parents who had to give approval for surgery on their children, or decisions on radical surgery. The sample diversified further over time to include other actors who were asked for their more or less conscious consent to the doctor's decision: the patient, his/her closest relatives, the parents of a minor, friends, occasionally other doctors. The press conveyed a notion of consent which consisted more in approval of decisions already taken by the doctor alone than in discussion and sharing of the decision and the reasons for it between doctor and patient. However, the need to convince patients in order to restrict their grounds for complaint generated the implicit idea that they had an active subjectivity able to understand and evaluate the risks of, and reasons for, medical choices.

A fruitful source of information on this composite situation is the *British Medical Journal*, a weekly founded in 1840, which besides being one of the medical journals most respected by the international medical community, was also the organ of the British Medical Association.

The term *consent* appears in the journal's issue of February 1842. It does so in an article on the case of a twenty-four year-old farm labourer with a gangrenous arm. Because the gangrene had spread to the man's shoulder, the doctor decided to amputate "before his consent to its removal could be obtained."[16] This reference to the need for the patient's consent to a medical decision was framed in a defined discursive context. In fact, the article discussed the patient's consent in relation to a case involving radical surgery – the amputation of an arm – and a severe and explicit medical condition, the gangrene having rapidly spread from the forearm to the entire limb. These two elements constituted an emergency condition identified as such by the self-evidence of the pathology and the suffering that it was causing. These two factors made a radical intervention socially recognizable and acceptable even in the absence of the patient's explicit consent.

Cases of radical or invasive surgery legitimized by suffering explicitly recognizable to all the actors on the medical scene (doctor, patient, family, friends), and who were thus induced to endorse the doctor's decision, are recurrent in the pages of the *British Medical Journal.* The consent given appeared to be *a posteriori* approval obliged by the urgent nature of the emergency; there was no participation in the medical decision but only ratification of a decision already taken. The severity of the patient's condition seems to have been the crucial factor inducing the actors, primarily the patient, to comply with the doctor's decision. In 1847, the thirty-six year-old Lot Organ, suffering with a diseased elbow, at first refused amputation of his arm but then consented to the operation with his "general health becoming injured."[17] The article in the *British Medical Journal* gives account of the patient's consent as a merely verbal expression resulting from his state of need. However, already in 1851, in a case of ovarian dropsy, there emerged a more complex meaning of the notion of the patient's consent. John Grant Wilson, a doctor at Bristol General Hospital, explained that he had decided to intervene with the radical choice of an ovariectomy on a twenty-four year-old woman suffering from ovarian cancer. Grant said that he had obtained her consent "having stated the case fairly to my patient, setting the risk on one side, and the advantage on the other."[18] Once again, the consent consisted in acceptance of a decision taken only by the doctor; but there are indications that the patient agreed with the reasons for that decision and had the capacity to understand and assess its merits. The radical nature of the surgery performed on the patient is the distinctive feature of the manner in which consent was given in these cases. The obvious lesion on the patient's body resulting from ovariectomy configured the doctor's action as potentially unlawful, for it constituted direct physical interference in the patient's body which might constitute the crime of assault and battery. This prospect emerged in the cases of ocular enucleation often reported in the *British Medical Journal*. In 1868, for example, Dr McKeand at the Manchester eye clinic, citing his own experience, emphasised that it was "a difficult task to convince the patient of the necessity of resorting to this procedure." The patient delayed the decision in the hope of the disease subsiding, and gave consent only "when the very mischief it was wished to avoid had commenced, and making its way with giant strides, leaves only the alternative of enucleation or total blindness."[19] Evident here is the extent to which the patient's consent to the radical surgery decided by the doctor was the prerequisite for surgery – to the point that the doctor was obliged to convince the patient of the goodness of his decision. The somewhat binding nature of the patient's consent to radical surgery emerged in other articles in the journal which reported cases of amputations or invasive operations not performed because the patients had refused to give their consent.[20] These cases show that consent functioned in that period as a formal guarantee for an operation foreseen as highly damaging to the patient's physical integrity and therefore likely, in the case of dispute, to lead to the doctor's indictment for injury or assault.

From the mid-nineteenth century onwards, articles in the *British Medical Journal* evidence a gradual diversification in the use of consent. Reported in 1851, for example, was the case of the parents of a child suffering from a neck tumour. Before consenting to the surgery proposed by the doctor, the parents had decided to obtain a second opinion on the "expediency of this treatment."[21] In April 1867, however, a report on a discussion held at the Obstetrical Society gave a new dimension to the issue of consent. This report dealt with reproduction and procreation, and it was therefore couched in gender terms. It concerned the notorious case of Dr Isaac Backer Brown, who had claimed that clitoridectomy was the surgical remedy for epilepsy. He had performed the operation frequently in his clinical work, as demonstrated by a book published in London in 1866: *On the Curability of Certain Forms of Epilepsy, Catalepsy and Hysteria in Females*. The Brown affair received wide coverage also in the non-specialized press because of the uncertainty of the therapy and the lack of consent of Brown's patients and their families to the operation[22]. The discussion at the Obstetrical Society focused on Brown's possible expulsion from the society because he had perfumed a clitoridectomy "without the consent, without the knowledge of the patient and her friends."[23] The verdict of the Obstetrical Society was plain:

> it would be difficult in such a case to draw the line between unscrupulousness and indiscretion, between fanaticism and fraud. But there were charges that operations had been performed upon women – mutilation they may be called – without the knowledge and consent of the unfortunate women or their husbands. Hysterical and weak-minded women are easily enough persuaded to submit to almost anything which they are assured will benefit them; but the mutilation of persons incapable of judgment without the consent of their natural protectors, and of conscious and intelligent women without their knowledge and consent, is a proceeding which the profession justly holds in horror.[24]

The discussion among the members emphasised that the patient's consent was much more important in this case because of the specific type of operation performed. By acting on the reproductive capacity, clitoridectomy had a crucial bearing on the quality of a woman's future relations, especially marital. The new physical condition of such women, in fact, would force them and their relatives to explain to marriage suitors that "they have been mutilated, and thus they are obliged to expose themselves to the possibility of being treated as imperfect persons."[25] In this case, the main injury was identified in the performance of a mutilative operation like clitoridectomy without consent of the husband in the case of married women, or the 'knowledge' of friends or relatives in the case of unmarried ones. The nature of the consent required from the patient thus appears to have changed from simple confirmation of the operation decided by the doctor. The same article, in fact, reported that when the woman was asked how aware she had been of the operation performed on her, she replied "that she did not know what had been done to her, that the nature of the operation had never been explained to her, nor had she been asked if she would consent to the operation."[26]

The case of the clitoridectomy performed by Brown raised the issue of consent also in the case of psychiatric patients, so-called 'lunatics'. The problem of how to treat mental disorders had been at the centre of medical discussion in Britain since 1845, when the Lunatics Act had instituted a National Lunacy Commission with jurisdiction over the detention and treatment of people with mental health problems in England and Wales.[27] The forms and methods of the medical treatment of such people had been discussed in legal and ethical terms by the Commission together with psychiatry. However, it was concluded that the question of the patient's consent "was not an issue"[28] because coercive measures against a mental patient could be legitimized by a doctor's order, without the consent of the patient or relatives. The issue of consent by mental patients was addressed in the columns of the *British Medical Journal* both directly and through discussion of alcoholism treatment. In 1879, for example, subject to discussion was whether alcoholics could be obliged to undergo detoxification. It was noted that the person "should be allowed to give an intelligent consent to that form of treatment which promises him the best hope of escape from the thraldom of drink."[29]

In the columns of the *BMJ*, consent by the patient – or those acting on his/her behalf – to medical treatment increasingly assumed the features of a legal guarantee protecting the doctor against lawsuits. A first occasion on which this linkage clearly emerged was in 1874, when the journal reported a debate on the murder law in the House of Commons which had explicitly discussed the "responsibilities of surgeons operating without consent."[30] The matter was mentioned in regard to the case of a doctor who had administered chloroform to operate on a patient, who had later died. During the parliamentary discussion, it was maintained that such action fell under the clause "Homicide by an act consented to by some one who has a legal right to consent to it is not criminal, if the act is done in good faith for the purpose for which it was consented to, and with due knowledge, skill, care, attention, and diligence."[31] According to the report on the parliamentary debate, the discussion centred precisely on the legal boundaries of medical-surgical treatment without consent, but it did not furnish a formal definition specific to surgical and medical work.

In these terms, the prime purpose of consent was to protect the doctor against possible charges of assault or negligence; but it also concerned violation of the body's physical integrity. Consent was consequently not conceived as recognition of the patient's autonomy of judgement and his/her right to decide on personal health issues. Thus, for example, in 1882 the *British Medical Journal* resumed a topic that it had already frequently addressed: the examination of a woman injured during an alleged sexual assault. The case of a doctor who had conducted a gynaecological examination on a woman without her consent was the occasion to discuss the legal obligations of medical action. Here consent emerged even more forcefully as a ground for defence and guarantee of the doctor's action because it concerned an intervention involving two such complex areas as sexuality and gender.[32] A further variant of legal consent emerged in regard to the vaccination of children. This issue set protection of a person like a child without legal autonomy against the collective need for prophylactic control measures to prevent the spread of diseases. In this case, priority was given to the collective need through a decision taken by the Public Vaccinator, who acted with the authority and on the instructions of the Local Government Board.[33] A similar conception of consent as an expression of somehow conscious assent by the patient to the medical choice emerged again in relation to health policy measures, and with specific regard to the movement of an infected patient from one place to another. The occasion was an article on the parliamentary debate on the Contagious Diseases Act, which formalized a request for "power to remove without consent, on a justice's order, whenever a patient cannot be properly isolated so as to prevent the spread of the disorder, or properly treated."[34] The predominance of the collective will over the individual patient returned in an article of 1888, when the journal published a summary of a speech by Henry R. Hatherly, surgeon at the Nottingham Hospital for Women and president of the Midland Branch of the British Medical Association, entitled "On Some Aspects of Abdominal Surgery." Hatherly spoke of various operations performed on women with epilepsy or "lunatics" and identified a social concern that overrode the issue of consent: "That lunatics or epileptics should become wives or mothers was very undesirable, and the preservation of their procreative powers was of less importance than in the case of the sane."[35] Hatherly suggested that written consent signed by the patient's legal guardian should be obtained prior to the operation, given that the state, as guardian of the insane, allowed the courts to give consent in such cases. The problem of surgical operations on people with mental problems remained undefined, and a few years later it again returned to the columns of the journal. In 1897, George H. Rohé, superintendent of the Second Hospital for the Insane in Sykesville, Maryland, addressed the issue from another point of view: "how a lunatic is competent to consent to an operation upon the latter." Rohé argued that the "character of the operation *per se* can have no influence upon the validity of the consent."[36] He continued:

> In absence of any specific enactment the general principle that no one can *invite* be touched by another obtains. Applied to surgical operations it, of course, requires the same quality of consent to open an abscess as to amputate a limb, operate for hernia, or remove the uterine appendages. The law must, so far as the technical assault upon the individual is concerned, deal with principles.

Rohé stressed that he was unable to determine the position taken by the English judges, whereas the American ones had identified the criteria with which to settle the issue. In periods when the 'lunatic' was sane, he was entirely capable of deciding; when he was not, the state, as "guardian of all insane persons," had the right to decide on his behalf. But, Rohé added, according to the American judges:

> The lunatic may, even if there is no absolutely lucid interval, be competent to give consent to the performance of an operation if he understands its object and consequences. It is the central principle of the modern law of insanity that the validity of any act of a lunatic depends upon his capacity to perform the particular act in question.[37]

Hence, according to Rohé's reconstruction , the doctor had a decisive role in this case because the patient's lucidity, and therefore his capacity to express consent, was defined by the doctor's analysis.

Whilst these examples suggest that the issue of the patient's consent increasingly concerned diverse aspects and events of medical experience, again in 1883 the *British Medical Journal* published cases demonstrating how the patient's consent to surgery was a significant factor in the decision. The journal reported the case of a patient with an intestinal obstruction for which the doctor had suggested a laparotomy, but he warned that "consent is not usually given to the operation until the patient is so far *in extremis* that recovery is impossible."[38] Again, consent seemed to be the final outcome of a state of necessity, where the self-evidence of the pathology and suffering safeguarded and guaranteed the necessity for surgery and mutilation. The evidence of the disease was used by the doctor, both as a decisive instrument with which to persuade the patient to consent to the operation, and as a decisive, socially recognized, guarantee of the legitimacy of his action.

The clash between the therapeutic needs identified and defined by the doctor and the patient's will was a constant feature of consent. On the one hand, it impeded recognition of the patient's consent as a prerequisite for any surgery; on the other, it did not exclude such consent from the set of possible options, given the doctor's risk of being indicted for injury or negligence. Despite this substantial ambiguity in thought on consent, from the last decades of the nineteenth century onwards the *British Medical Journal* increasingly focused on the legal nature of consent. In 1890, for example, the journal published an article on "the right to perform operations in hospital." The article asked whether a hospital surgeon had "the right to perform an operation on a child without the consent of its parents."[39] The case involved a child afflicted by coughing fits. After fruitless therapy, an operation had been performed on the boy despite the mother's refusal to give her consent. The woman had immediately protested, alleging that the doctor had no right to operate without her permission. The situation had deteriorated further because, after further surgery, the boy died. The doctor defended himself by claiming that, given the circumstances, if he had not operated, "he should have been gravely neglecting his duty."[40] In court he declared that he had acted correctly. Given that the boy was in mortal danger, if he had not done something because the parents had withheld consent, "he would at least be guilty of gross inhumanity."[41] This was reaffirmation of a concept rooted in the relationship between doctor and patient, namely that the best guarantor of the patient's welfare is the doctor himself. The coroner further confirmed this position by stating that a jury would probably have convicted the doctor if he had acted otherwise: that is, if he had not performed the operation because he had not received the parent's consent, although it might have saved the patient's life. In the following year, the relationship between the patient's will and the purposes of care was considered from another perspective in an article which inquired whether voluntary admission to hospital constituted implicit acceptance of all the medical decisions that the staff of that hospital might take. The article was a review of a book on legal medicine written for hospital managers – Leonard Syer Bristowe, *Legal Handbook for the Use of Hospital Authorities*, London: Reeves and Turner in 1893 – from which the following passage was quoted:

> No operation ought to be performed without the express consent of the patient, or, if he is not in a position to give such consent, of his nearest relatives; nor ought it to be carried farther than is warranted by such consent; and although the precise extent of an operation must often be left to the

> discretion of the operator, yet the consent of the patient should be founded on full knowledge of what the nature and possible extent of the operation will be, and of the consequences which it may involve. Disregard of these rules may, apart from any question whether the operation has been skillfully or unskillfully performed, entail responsibility to the operator.[42]

At the end of the century, the *British Medical Journal* reported a final significant case concerning the issue of consent. In 1896, the journal published a series of articles on the *Beatty v. Cullingworth* case. This concerned a patient who had consented to a ovariectomy on one of her ovaries. But both ovaries were removed because, during the operation, the surgeon had discovered that the other ovary was diseased. The woman sued the doctor because she had not consented to the removal of both ovaries; consequently, the doctor did not have permission to remove them. The journal published several articles on the trial, which ended with an acquittal based on the presumption that the woman would have agreed to a double ovariectomy if she had known that both ovaries were damaged. But the case is interesting because the *British Medical Journal* drew on the affair to state a clear position on the patient's consent to surgery. In an article of November 1896, the journal noted that the defence of Dr. Cullingworth had only one weakness: the fact that "the consent given to him was tacit, implied, not even verbal, much less in writing."[43] The journal took a very clear position on the problem:

> The moral is: Before doing an operation surgeons should be careful to explain what they propose to do, and get unequivocal consent from the patient, or, if the patient is not in a condition to give consent, from the patient's nearest friends. Such consent should be either in writing or distinctly expressed before witnesses.[44]

The foregoing survey of articles in the *British Medical Journal* has confirmed the progressive formalization of patient consent to medical decisions. However, it has also shown that the purpose of this formalization was more to protect doctors against possible indictments than to affirm the right of patients to participate in decisions about their health. Put in these terms, consent was an issue poised ambiguously between further formalization and leaving the doctor entirely in charge of medical decisions and their contents. A largely similar situation is apparent when the attention moves to France, where the absence of explicit reflection on consent seemed more pronounced and the prevalence of the paternalistic approach more evident. The constraint on the doctor's action consisted, not in the patient's right to express an opinion, but in the patient's objective interest as defined by the doctor.[45]

A first source that makes it possible to track the diachronic changes in this idea or its semantic field is the *Bulletin de l'Académie Nationale de Médecine*. The Académie was created by royal decree on 20 December 1820 to "answer questions from the government on everything to do with public health," and it was also the prime authority for formal evaluation of new scientific knowledge in France.[46] The term *consentement* appeared in the very first issues of the *Bulletin*, but it referred only to the medical community's consensus in confirming and validating therapeutic practices or theories. In 1849, however, a report on a case of urethral stricture made the first reference to the patient's consent to surgery. The text is succinct, but it is possible to infer that the patient had been given some information about the operation, given that the text states that "frightened by this new treatment, the patient refused his consent" and then went to another hospital and consulted a different doctor.[47] The diriment nature of the patient's consent to surgical operations reappeared a few years later in another report by Jean Depaul, this one on obstetric practices and the use of ergot. After discussing the fears and emotions aroused in the family by the sight of the obstetric and surgical instruments, Depaul added: "the unfortunate patient, from whom it was necessary to obtain consent, repeatedly did not give it because of fears which doubled the necessary preparations, and because of her desire to give birth to a live baby." Depaul therefore suggested that the woman be administered some drops of ergot to calm her and thus gain her consent.[48] Whilst references to consent are sporadic and brief in the periodical of the Académie Nationale de Médecine, the topic appears more frequently in the literature on legal medicine. Here the question of consent was treated in more structured and meaningful manner. The perspective from which consent was addressed was mainly that of publications on surgery. In 1873, for example, it was discussed by Jean-Casimir-Félix Guyon, founder of the French school of urological surgery, in his *Éléments Clinique de Chirurgie, comprenant le Diagnostic Surgical, les Opérations* published in Paris in 1873. In regard to the general principles that should regulate surgery, Guyon mentioned the patient's consent resulting from his/her confidence in the surgeon:

> The prerequisite for convincing the patient is inspiring his confidence, and the care itself, which examines everything to appraise the situation with attempts at internal treatment if necessary, are the surest means to obtain it. When the patient is aware that everything has been discussed and weighed,

> that nothing regarding his interests has been overlooked, it is usually not very difficult to have him understand the necessity of the operation, and if he does not desire it, at least submit to it with resignation. It is in fact essential to obtain the patient's free consent before the operation.[49]

The only two exceptions to this principle were children and the insane. In these cases, consent was obtained through an asymmetrical interpretation of the doctor/patient relationship as a formal expression of trust in the doctor's decisions and actions. From this point of view, according to Guyon, consent was not recognition of the patient's active role in the relationship with the doctor and the decision-making that concerned him. On the contrary, Guyon believed that the doctor/patient relationship was hierarchical:

> As [Alfred Armand Louis Marie] Velpeau rightly said, "our duty is to show patients what is most suitable for their disorders, to enlighten them about the dangers to which they are exposed if they refuse to submit to the correct remedy; but they still have the right to do or not to do what we recommend to them." In those distressing situations where the surgeon must contend with the pusillanimity, discouragement, or low intelligence of his patients, he must deploy all his resources, use all the means suggested by the spirit and the heart, speak softly or severely according to the circumstances, seek help from the patient's family and his loved ones, to convince him, and only desist when he has used all the means available. However, he also has the duty to respect the free will of all individuals in possession of their faculties.[50]

Providing indirect confirmation of the relative role of consent in French medical doctrine is a book by Ferdinand Dubrac, president of the civil court of Barbezieux, entitled *Traité de Jurisprudence Médicale et Pharmaceutique*, published in 1882 by Baillière in Paris. Devoted to informing doctors about the legal implications of their work, the book did not include the issue of patient consent among those sensitive in medical terms. Likewise, there is no trace of the notion of consent in the 1845 book by Max Simon, *Déontologie Médicale, ou des Devoirs et des Droits des Médecins dans l'État Actuel de la Civilisation*, published by Baillière in Paris.

However, consent was discussed by books specifically devoted to legal medicine. In 1890, the two lawyers Leonce-Charles Guerrier and Alexandre Louis Rotureau-Launay published a manual on legal medicine in which they wrote as follows on the subject of experimentation on patients:

> The end, however scientific, cannot justify the means, and whatever interest there may for mankind as a whole to solve an obscure problem, this does not allow a doctor to indulge in experiments on patients. Undoubtedly, in some cases, the patient's consent may shield the doctor from any responsibility, but besides the fact that it is necessary to establish the total freedom of this consent and full knowledge of the facts by the person who has given it, we confess to considering this justification as almost always insufficient in the case of an experiment's failure. In fact, the Court of Cassation has decided, with a decree of 21 August 1851, that although the victim's consent is a mitigating circumstance, it is not a justification.[51]

As in the British case, the notion of consent was entirely declined in terms instrumental to protecting the doctor. Indeed, when Guerrier and Rotureau-Launay discussed fees and payments, they recommended paying close attention to the transaction, because the doctor could easily be taken to court on the "pretext" that the patient's consent had not been given. To be emphasised is that, also in the French case, consent arose in a sort of indefinite discursive space, where it was feared as a legal possibility and rejected as an ethical and professional constraint.

In 1898, a doctoral thesis at the Paris Faculty of Law, devoted to the relationship between medicine and law, and written by Albert Salomé, explicitly discussed the issue of consent to surgery. In regard to liability, Salomé explained that the doctor was entirely free in his decisions on treatment and means, with the sole legal constraint that he must obtain prior consent from the patient:

> According to case law, a doctor cannot, except in emergencies, legitimately perform a surgical operation without having been previously authorized by the patient or the person under whose authority the patient has been placed. Proof of this consent is incumbent upon the doctor. The authorization may only be tacit and implied by the circumstances or a set of facts (1). Operating without the patient's consent may give rise to a civil action, but not to charges of incompetence, carelessness, inattention, negligence or disregard of the regulations set out in Article 319 of the Criminal Code; the doctor cannot subsequently be subject to any penalty (2). On the other hand, although the doctor may, in principle, be liable for gross malpractice, he cannot be blamed for being wrong in his diagnosis and refusing to perform surgery, the results of which are always problematic (3).[52]

The prescription of the patient's prior consent to surgery, however, did not appear to stem from any decision formalized in law; rather, once again, it was a purely precautionary measure to protect doctors against possible claims and suits brought by their patients. Indirect confirmation that the issue of consent had no definite legal formalization is provided by the entry *responsabilité médicale*, written in 1876 by Gabriel Tourdes professor of legal medicine at the University of Strasbourg, for the celebrated 100-volume *Dictionnaire Encyclopédique des Sciences Médicales* edited by Amédée Dechambre and published in Paris between 1864 and 1889. Tourdes described experiments which he considered to fall under article 311 of the Criminal Code relative to bodily harm. He emphasised that "Duties towards science must give way to the respect due to the patient."[53] In this regard, he cited the notion that no patient should be subjected to a life-threatening therapeutic experiment unless the purpose was to prevent an even greater danger. This was the classic paternalistic idea of Hippocratic origin that the doctor was the sole guarantor of the patient's health, and that only the doctor could identify the patient's interests. However, Tourdes alluded to the need to safeguard medical action in two particular areas where the doctor's liability was especially at issue: obstetrics, where multiple relationships, present and future, were involved; and surgery, where doctors were at risk of possible indictment for injuries caused by invasive operations. It should also be pointed out that Tourdes – in the manual on legal medicine which he published in 1896 – did not speak of consent except in relation to marriage and to matters concerning sexual violence.

Despite the evidence of a relative presence of patient consent in the French debate, towards the end of the nineteenth century there are signs that some sort of formalization of this option was under way. In 1898, the newspaper *La Presse médicale* reported that the general assembly of the Conseil Municipal of Paris had been notified of an amputation performed on an eighteen-year-old girl in the hospital La Salpêtrière without parental consent. Although the hospital administration had rejected the claim that the parents were unaware of the need for the operation, the assistance publique had nevertheless issued an internal circular to all hospitals stating that, in cases of necessity, when the service head foresaw an "operation presenting features of gravity," if the parents refused to consent to the operation, they must put their refusal in writing.[54] A few years later, the relationship between the doctor's liability and the absence of consent was explicitly addressed in the columns of the *Annales d'Hygiène Publique et de Médecine Légale*. The journal reported a conference of Parisian barristers during which the civil liability of the doctor was discussed in the specific case of a mutilating operation performed on a woman without her consent. Because the woman had been severely ill, the doctor had opted for radical surgery. The woman's life had been saved, but she sued the doctor for the permanent damage that she had suffered. According to the journal's account, the barristers discussed the legal bases that had allowed the doctor to decide. They concluded that, although the doctor "perhaps also believes that he is invested by the law with a qualification that consecrates the knowledge acquired, he must be the sole judge of the situation."[55] In other words, the crux of the problem was identifying who had the right to take medical decisions: the patient or the doctor. The answer by the barristers was significant because it cited reasons concerning the professionalization of medicine:

> The doctor's professional obligations and his social role require that he must be in charge of the treatment. The doctor has the duty to do whatever is necessary to save the patient entrusted to his care. This duty includes the correlated right to choose the techniques used to achieve the purpose: namely recovery.[56]

Hence, because the doctor's competence was the result of a professional training process managed and controlled by the state and the law, his unilateral decision to operate was "not the violation of a right but, on the contrary, the exercise of a right implicitly conferred by the law.[57] The Parisian barristers added two further justifications for this decision-making procedure. The first was a matter of fact: in emergencies it is difficult for doctors to consult patients, relatives, friends, or other doctors. The second justification was that the risk of complaint would obstruct the adoption of radical clinical measures deemed necessary, besides cases in which the patient was unable to express an opinion:

> But why confront the doctor with this alternative: either ask incompetent persons, considered such because they are third parties extraneous to the art of healing, for authorization to act or, in the absence of consent, apply the let-die principle?[58]

Confirmation of the guarantee provided to doctors by professionalization is also provided by the writings of one of the authorities of French medicine at the time, Paul Brouardel. Since 1879 successor to Ambroise Tardieu as professor of legal medicine at the Paris faculty of medicine, Brouardel wrote a 12-volume *Course de Médecine Legal*. This collected his lectures, which interwove rigorous legal analysis with a specific clinical perspective. Brouardel briefly discussed the patient's consent in the volume devoted to *Exercice de la Médecine et Charlatanisme*, in which he mentioned the patient's consent only with reference to surgery:

> Before I conclude what I have had to explain to you about surgery in general, there is a final recommendation that I believe should be made: when you decide that a surgical operation on a patient aged under twenty-one is necessary, do not forget that you must request and obtain approval from the parents; for they alone can give it: the authorization of the minor patient is inadequate to guarantee the surgeon's non-liability, either in private practice or hospital.[59]

Once again, the purpose of gaining the patient's consent was to protect the doctor, not to grant the patient the right to govern his/her body autonomously. In this regard, Brouardel advised his students to pay maximum attention to operations on married women, never forgetting to ask the husband for permission. Brouardel believed that this was just as indispensable as the parents' permission when an operation concerned a child. This added a further significant aspect to the decision-making process, because in subsequent years French medicine repeatedly considered extending marital authorization to the medical sphere when surgery on a married woman was to be decided.

Brouadel's observations concern an area in which French medicine had often addressed the issue of consent: obstetrics and the legitimacy of abortion when the mother was at risk. The Académie Nationale of Paris had discussed the matter at length in 1851 – as had its counterpart in Brussels – and its decision to accept the operation as morally and professionally legitimate resonated throughout the international medical community.[60] Hence, the relationship with consent emerged more explicitly in obstetrics than in surgery. The entry *avortement provoqué*, written in 1867 by Jean-Marie Jacquemier for the *Dictionnaire* edited by Dechambre stated "the purpose and consequences of the operation should be explained to the woman so that she can undergo it freely and in full cognizance of the facts. Although the consultation is not absolutely compulsory, it is wise not to abstain from it, given that abortion can always serve as the basis for criminal investigation."[61] This passage shows that a woman's consent was not sought because she had a formal or substantial right to decide on the health of her body, but because her approval helped ensure the doctor against criminal prosecution. The French criminal code, in fact, did not envisage the case of therapeutic abortion, so that a doctor who performed this operation was formally liable to prosecution for procured abortion. Moreover, it should be emphasised that no doctor was indicted because he had procured an abortion for therapeutic purposes. The reasons why the woman's consent was neither necessary nor sought stemmed from the paternalistic attitude and the stereotype of the woman as pertaining to an emotional-natural sphere which limited her capacity for rational thought. According to Stéphane Tarnier, director of *Clinique d'Accouchement* of Paris and Pajot's successor to the chair of obstetrics at the Paris faculty of medicine, a woman did not have the resources to cope with the gravity of her situation. She was too personally involved and too weak to make rational choices. To this one might add – perhaps somewhat over-stretching the interpretation– that the women of whom Tarnier spoke had been hospitalized, and historiography has shown that such women mostly belonged to the most vulnerable sections of society. Accordingly, a factor in the exclusion of female consent seems also to have been a desire not subject the authoritative decisions of science to the will of a probably illiterate woman – or at any rate, a woman deemed to lack the knowledge necessary to understand the gravity of the issues involved. Added to this is the fact that, as Léonard wrote, nineteenth-century hospitalization was often based on a tacit exchange between the gratuitousness of care and the hospital's use of patients for experimentation.[62] Tarnier had addressed the question of the woman's consent in these terms in an entry on *embryotomie* written for the *Nouveau Dictionnaire de Médecine et de Chirurgie Pratiques* in 1870.[63] In abstract he had recognized this right; but in concrete he had then denied that the right existed in power relations at the moment of childbirth, on the grounds that the woman would not be mentally and physically able to cope with the weight of responsibility for the decision. In equally rigid terms, Louis-Joseph Hubert, professor at Louvain, had written that obstetric operations "are facts that pertain to the doctor, for which he assumes all responsibility, and he must ask his own conscience and not the patient's whether they are legitimate."[64]

Hence, the consent of the woman as such was rarely discussed, because it was crushed between the two organicist polarities of religious morality and science. The conflict between views centred on an organicist interpretation, on the one hand, and those on the primacy of the doctor on the other, became overt during the Amsterdam international congress of gynaecology and obstetrics of 1899. On that occasion, the deputy prosecutor general of the court of Bordeaux, Joseph Maxwell, clashed with Alphonse Pinard, an eminent French obstetrician and founder of the French École de Puériculture of the Paris faculty of medicine. Maxwell attacked Pinard for a speech delivered to the international congress of medical sciences held in Rome five years previously, and in which Pinard had expressed his views on obstetric abortion and the woman's consent. For Maxwell, the speech potentially constituted a criminal offence because it advocated therapeutic action without the patient's knowledge. It therefore appeared to be a "violation of the right that pertains only to the patient, or those who represent her if she cannot express her will, to determine the conditions in which she authorizes any intervention in her body's integrity."[65] Pinard's reply was consistent with what he had always maintained: Maxwell's assertion was a simple attack on the "the free and full exercise granted by the diploma, which is a right that I have always claimed and for which I shall fight relentlessly and forever."[66]

The foregoing survey on British and French medical discourse has furnished material useful for historiographical analysis of informed consent. First, it has shown the extent to which the patient's consent was a theme present in medical discourse in both the British and French contexts. But it was used from a specifically defensive perspective. It was a resource sought by the doctors to protect themselves in medical practices especially liable to expose them to the risk of prosecution. In the century when the professionalization of medicine was beginning in several countries, doctors worked in certain areas outside the protection of the law, which did not explicitly envisage certain kinds of medical action performed for therapeutic purposes. This was the case of radical surgery with amputations and mutilations; and it was also the case of obstetrics, which by acting on reproductive capacity and kinship ties – especially if use was made of abortive therapies – exposed the doctor to the risk of indictment. In these areas, doctors were protected only by the profession and the public dimension of their actions. Hence an implicit demand for legal recognition of the specificity of the medical motive for actions potentially punishable by law was a constant in the medical discourse. The survey of the British and French medical press has shown that consent arose in explicit and binding manner almost solely in relation to surgical amputation or mutilation, or obstetric operations affecting procreation and the definition of kinship ties and inheritance. These were two situations where medical action had self-evident damaging consequences if measured on a legal semantic that did not recognize the specificity of the medical profession, its action, and its purposes. From this point of view, the *British Medical Journal*, like the French medical press, demonstrates that essentially extraneous to the conception of the patient's consent was the idea that patients had a right to be actively involved in decisions about their health and their bodies. It is equally evident that patients were asked to confirm choices and decisions made solely by the doctor *a posteriori*, without being able to make substantial changes to them.

Historiographical interpretations of the nature of patient consent before 1957 are thus substantially confirmed by consideration of the nineteenth-century British and French medical press. But those publications also furnish elements with which to evaluate patient consent before the twentieth century; a matter which should be subject to further inquiry. A first element that warrants investigation is the fact that, by granting the patient a legal personality such to constitute a risk of indictment for the doctor, the medical discourse implicitly assumed that the same patient had some sort of active role in medical practice. In this regard, the English and French medical press shows that in order to obtain the patient's consent – with the urgency of persuading him/her of the goodness and the necessity of the medical decision – the doctor often went so far as to give detailed account of the reasons for his decision. He thus shared the risks and benefits of that choice. Certainly, the relationship between doctor and patient remained asymmetrical, given that the latter was asked to agree to something that had already been decided by the former. But it is undeniable that the features of communication in regard to medical decisions were evolving significantly.

This dynamic seems to have been fully part of a professionalization process aimed at making medical expertise a key biopolitical device, and where definition of the doctor's role and the guarantee of margins of autonomy in his therapeutic action was a prime area of investment by medicine itself. In this context, the lack of legal recognition of the specific autonomy of medical action was a decisive problem for medical practice. Hence the fundamental purpose of medical discourse was to obtain legislation that recognized the power, possibilities and responsible autonomy that such practices concretely expressed. In this endeavour, the defensive function of patient consent was a major factor bound to ramify further in relation to the increased capacity for action and intervention of medicine itself.

Notes

1 See for example: Jessica W. Berg, Paul S. Appelbaum, Charles W. Lidz, Lisa S. Parker, *Informed Consent. Legal Theory, Clinical Practice* (Oxford: Oxford University Press, 2001); Grzegorz Mazur, O.P., *Informed Consent, Proxy Consent, and Catholic Bioethics. For the Good of the Subject* (Dordrecht-Heidelberg-London-New York:

Springer, 2012).

2 See Paul J. Weindling, *Nazi Medicine and the Nuremberg Trials. From Medical War Crimes to Informed Consent* (New York: Palgrave Macmillan, 2004); Jenny Hazelgrove, 'The Old Faith and the New Science: The Nuremberg Code and Human Experimentation Ethics in Britain 1946-73', *Social History of Medicine*, 15, (2002), 1, 109-135.

3 Hazelgrove, 2002; Claire Hilton, 'Changes Between the 1959 and 1983 Mental Health Act (England and Wales), with Particular Reference to Consent to Treatment for Electroconvulsive Therapy', *History of Psychiatry*, 18 (2007), 2, 217-229; Jesper Vaczy Kragh, 'Malaria Fever Therapy for General Paralysis of the Insane in Denmark', *History of Psychiatry*, 21 (2010), 4, 471-486; Barron H. Lerner, 'Beyond Informed Consent: Did Cancer Patients Challenge Their Physicians in the Post–World War II Era?', *Journal of the History of Medicine and Allied Science*, 59 (2004), 4, 507-521.

4 Ruth R. Faden, Tom L. Beauchamp, *A History and Theory of Informed Consent* (New York-Oxford: Oxford University Press, 1986); Emmanuel Betta, *Animare la vita. Disciplina della nascita tra medicina e morale nell'Ottocento* (Bologna: Il Mulino, 2006).

5 Walter J. Friedlander, 'The Evolution of Informed Consent in American Medicine', *Perspectives in Biology and Medicine*, 38, 3 (1995), 498-510.

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Cultures, communication and representations

Chapter Five

Culture, health and communication in the doctor/patient relationship: theory and practice

Ivo Quaranta

> The systematic neglect of culture in health and health care
> is the single biggest barrier to the advancement of the
> highest standard of health worldwide.
>
> Lancet Commission Report on Culture and Health[1]

Introduction

Doctor/patient communication has been the subject of numerous anthropological studies within the broader analyses of the social and cultural dimensions of therapeutic practices. In the early 1970s, a new strand of inquiry began to deal systematically with biomedicine in terms of a social enterprise embedded in a specific historical and cultural context from which it derives its values, ideas, and care practices.[2]

In those years an increasing emphasis on these dimensions began to emerge also within biomedicine: consider the central importance given to communication in the celebrated essay by Hampton and colleagues of 1975, which concluded with the following recommendations:

> Firstly, physicians can allocate the relative time spent taking the history and examining the patient with some confidence, knowing that the extra time spent on the history is likely to be more profitable than extra time spent on the physical examination. Secondly, more emphasis must be placed on teaching students how to take accurate histories in a medical clinic, and proportionately less on showing them how to elicit physical signs. Thirdly, more emphasis must be placed on research into communication between

> the patient and his physician, and perhaps less emphasis is needed on the development of new laboratory services. Fourthly, there are implications for the planning of medical outpatient departments. There needs to be more emphasis on space for interviewing patients, and proportionately less on space for examining them. Our findings also have implications for the number of follow-up appointments that need to be given to patients who seem to present diagnostic problems. It seems that if the physician is still in considerable doubt about the diagnosis after the history has been taken and the patient has been examined, then laboratory investigations are unlikely to be helpful.[3]

It is no coincidence that it was precisely in those years that it was deemed necessary to develop a 'new medical model' centred on a bio-psycho-social approach capable to flank the anatomical-physiological factors of illness with its personal and social dimensions.[4] The aim of these proposals was to enhance the efficacy and efficiency of care practices.

In that cultural climate, anthropological studies analysed biomedicine as a specific form of ethnomedicine culturally characterized by a focus on the anatomical-physiological dimensions of the individual biophysical organism.[5] The aim of those analyses was not only to highlight the historical-cultural nature of scientific and medical knowledge and practices, but also to demonstrate that 'sickness' itself should be viewed as a symbolic reality: indeed, there are specific cultural norms which qualify a particular state of being as a medical problem. If 'health' and 'sickness' are cultural categories, it is necessary to investigate the relationships that specific value systems may have with clinical settings, not only from the standpoint of the patients but also from that of the health professionals (doctors, nurses, auxiliaries, administrators, etc.).

It was on these premises that Arthur Kleinman and colleagues at Harvard proposed that biomedical categories should be regarded as cultural categories by which a particular interpretation of illness is constructed. "Disease" was thus conceived as a symbolic reality and medicine as a hermeneutic enterprise.[6]

This was the background that led to the proposal to distinguish between *disease* and *illness*.[7] With *disease* these authors referred to alterations in the functioning and/or structure of the individual organism. By *illness* they meant the personal experience of suffering. Disease and illness, therefore, were seen as two different explanatory models: the former rooted in the scientific language of the clinician; the latter in the patient's familial and social context.

The doctor/patient encounter was thus recast as a performance in which two different cultural constructions of the clinical reality are enacted; two constructions, however, often in conflict with each other. According to these authors, these considerations are of utmost importance, given that conflicts in medical communication are the main cause of non-compliance and therefore of therapeutic inefficacy.

An example is provided by Blumhagen's study on hypertension in North America. Patients interpreted their hypertension through folk models which identified the cause of the problem as the stress and tension that people experience in their lives (illness), whereas doctors configured the problem in terms of arterial blood pressure (disease). These different models led to non-compliance because, when the patients had passed the critical stages of their lives, they no longer felt under pressure and stopped taking their medications – which instead, given the chronic nature of the disease, they should have taken daily.[8]

Not taking the patients' perspective into account may hamper formation of an alliance between doctor and patient in regard to compliance with the therapeutic regimen. Ignoring the meaning that patients give to their illness means also ignoring how those patients will interpret the instructions given to them during the medical encounter.

Some authors therefore proposed that the doctor/patient relationship should include time devoted to exploring patients' beliefs about their disorders, the purpose being to prevent possible conflicts of interpretation between the clinician and the patient.[9]

Improving communication between doctors and patients, therefore, would enhance the efficacy of the therapeutic system by ensuring the compliance of patients with the instructions given to them by doctors. It also related to medico-legal provisions requiring the patient's involvement in definition of his/her therapeutic plan.

These notions have certainly had significant impact in the biomedical field. Consider the gradual transition from the model of informed consent to that of informed choice, and then to that of shared decision-making.[10]

However, ensuring patient compliance with therapeutic instructions and sharing legal liability are strategies which raise a number of critical issues. Is promoting biomedical efficacy always good, even when it takes the form, for example, of the medicalization of social phenomena? Is improving communication with patients sufficient to ensure their best interests, even when the factors harming their health are their socio-economic circumstances?[11]

It is evident that not only is communication alone not necessarily the best way to promote the patient's best interests, but it may also generate further problematic outcomes.

There is no doubt that centring the therapeutic encounter on systematic exploration of the patient's perspective provides the clinician with crucial guidance in his/her diagnostic and therapeutic work. However, it is also clear that such exploration is unlikely to happen if dignity is not granted to the patient's perspective – certainly not in terms of paternalism or general respect for others, but to ensure the clinician's proper performance of his/her work.

However, granting dignity to the patient's perspective entails simultaneous recognition of the cultural nature of biomedical practices. As the writers of the *Lancet* report on culture and health put it:

> Health-care providers should also acknowledge their own cultural values and consider them as such, and organisations should invest in understanding how their practices and values are cultural. Culture is not something that irrationally limits science, but is the very basis for value systems on which the effectiveness of science depends.[12]

Recognizing the cultural nature of clinical work does not mean delegitimizing it. Rather, it means becoming aware that at the core of clinical reasoning is an implicit cultural selection process liable to neglect dimensions that may otherwise be decisive in the diagnostic-therapeutic process. But what concept of culture is required?

Beyond the communication of information: the right to meaning

The approach based on the distinction between disease and illness sought to produce an anthropological concern with the perspective of patients, the purpose being to understand what biomedical criteria would otherwise have concealed. Whilst the aims of this approach are certainly still valid, its implementation at clinical level has often been problematic.

One of the consequences of the biomedical adoption of this approach has been a distorted notion of culture. Indeed, the founders of the approach subsequently proposed a substantial revision of it.[13]

Yet, in the health sector and beyond, culture is often seen as something that people 'have' as members of a group, rather than something that they also 'do' (in terms of cultural competence[14]). The conception of culture as a system of socially shared symbols used to interpret reality has often generated the belief that patients' interpretations should be related to some cultural pattern. This belief has fuelled a reductive view of cultural dynamics which is unable to take account of the multiple forms that differences assume, not only between cultural systems but also within them: differences of gender, generation, socio-economic status, religion, sexual orientation, and so forth.

> Cultural competence training at its worst creates an idea of culture as a thing "made synonymous with ethnicity, nationality and language," and that can be taught as though it can be satisfied using a checklist—do this, not that. Under such conditions, doctors who have been trained in cultural competence can often misattribute cultural reasons to patient issues, rather than recognise that patient difficulties can be equally economic, logistic, circumstantial, or related to social inequality. Those studying health care need to appreciate what is as yet unknown and the processes by which new knowledge can be obtained. To teach culture as a fixed perspective on illness and clinical behaviour risks the promotion not only of mediocre care, but also of poor strategies to address difficulties that emerge in socially complex treatment environments.[15]

An essentialist view of culture precludes not only understanding of the specific social meanings and dynamics that inform the patient's experience but also consideration of the patient's role as a cultural actor. This has been a key issue in the rethinking of therapeutic efficacy, as we shall see below.

The 'boxification' of culture[16] obscures the processual nature of the production and negotiation of meanings. It is for this reason that, in medicine, an operational definition of culture in terms of something people *do*, not simply as the conceptual baggage that they *have* as members of a group, can afford greater scope for action.

In fact, culture has been increasingly considered in anthropology as "something always in the making."[17] This is not to bracket off the deep-lying historically dimensions of cultural dynamics; but rather to emphasise the need to grasp *also* the ways in which cultural actors creatively appropriate collective repertoires of knowledge and practices, thus demonstrating the intrinsically open and dynamic nature of cultural production.[18]

According to Arjun Appadurai[19]: culture is a dialogue between aspirations and sedimented traditions. Ignoring one of the two poles of cultural dynamics is therefore likely to generate forms of reductionism. Considering only the "weight of history" confines cultural actors to their mechanistic membership of a context. Likewise, considering only their active role is likely to privilege an individualism unable to grasp the subtle and often implicit cultural logics that underpin individual behaviour.

These considerations become eminently practical when we focus on the experience of illness. Many studies have shown that what characterizes the experience of illness is often the difficulty of the sufferers to place themselves within a scenario of sense. This makes especially frustrating the work of those who – although they have the best intentions – come up against the absence of a perspective to be considered.[20]

Illness, in fact, does not occur solely at the level of the body that we *have*; it does so also at the level of the body that we *are*: the body in the world. The idea that the body is exclusively a somatopsychic organism on which to intervene technically has erased appreciation of the body as the existential ground of self and culture.[21] Not only are we bodies, but our bodies are also the active subjects of experience. They actively participate in the production of the meanings by which we interpret reality and qualify our experience of it.

Anthropology considers humans to be biologically incomplete. It does so because the information transmitted at biogenetic level is not sufficient to ensure our survival.[22] It is only within a social group that welcomes us that we learn the conceptual techniques and tools which enable us to orient ourselves actively in the world. As emphasised by Francesco Remotti,[23] we undergo a second social birth consisting in the cultural completion of the human being. Human nature is thus understood as constitutively cultural. What is universally human is precisely our dependence on specific processes of cultural construction: the very source of the difference that is an irreducible dimension of human nature.

However, distinctive of our forms of experience is a profound elision of the collective historical-cultural dimensions of human nature. This elision is inherent to the processes by which the human being is cultural moulded. These, in fact, are processes that come about informally through exposure to a social world from which we embody the values and symbolic forms that simultaneously mould our selves and our attitudes to reality. We may thus speak of ontological complicity between the person and the world, by virtue of the fact that we interpret reality through the cultural processes that mould us.[24] In other words, we relate to the world through the processes of our cultural moulding.

The body is not a marginal element in this process of reality construction and concealment of our generative role. On the one hand, knowledge and the social order are naturalized through their inscriptions in bodies. As they penetrate lived experience, their historicity and contingency recede from the sphere of awareness. It is through this embodiment process that the social order assumes the appearance of naturalness and necessity, and that the socio-political processes supporting it become opaque in the immediacy of lived experience. On the other hand, it is as culturally informed bodies that we perceive the world, interpreting it perceptually before subjecting it to explicit linguistic and cognitive reflection. As suggested by phenomenological theory, on perceiving the world, we have intentionality towards it before we categorize it. Because this process is pre-categorical, pre-objective and pre-conceptual and hence perceptual (but not pre-cultural) humans are cultural constructors of reality without necessarily being aware of it.[25]

Of course, the crisis of the body produces a crisis in our being-in-the-world because it undermines the bodily roots of signification. Yet we certainly cannot reduce the nature of cultural processes to the dimensions of subjective experience alone; we must instead consider experience in terms of the lived dimension of cultural processes. Because illness undermines the experiential dimensions of signification – its corporeal roots – it provokes a crisis in the silent, though constitutive, process of meaning production whereby we experience reality 'as if' it were autonomously endowed with sense. It is thus that the experience of illness engenders dissolution of the lived world, i.e. of the network of intersubjective meanings on which our usual experience of/in the world is implicitly grounded.[26]

If the experience of illness is characterized – although Ernesto De Martino[27] showed that numerous human experiences are subject to the process by which our being-in-the-world can enter crisis – precisely by a crisis of our role as cultural actors, mere extrapolation of the patient's perspective will be difficult. Rather than conceiving the personal interpretation of illness as something patients *have*, once we look at culture as an intersubjective process of meaning production by which we interpret reality and define our experience of it, personal interpretation should be regarded as something that must be *done*.

If culture is an intersubjective process, the doctor/patient relationship should be re-thought as a context in which the various parties involved co-construct meanings: it thus takes the form of a cultural practice. In this light we can also attempt to rethink the 'patient's best interest'. Illness, in fact, undermines the assumptions on which our everyday existence relies, and it forces us to renegotiate them. It is evident that this is a process affecting the entire network of interpersonal relationships within which experience is processually lived and defined.

We usually think that patient's best interest is granted by his/her involvement in decision-making through informed consent. The *logic of choice* at the core of the biomedical model of patient participation is culturally bound up with broader assumptions of social reality and on a definition in individual terms of the person as a "bounded, unique and more or less integrated motivational and cognitive universe, a dynamic center of awareness, emotion, judgment and action organized into a distinctive whole and set contrastively both against other such wholes and against its social and natural background."[28]

In the biomedical field, we find a clear reflection of the general idea that people's rights should be tied to the protection of their freedom to make choices. As Anthony Giddens argues, this is purely a historical and cultural idea. He describes the self in contemporary age as a project "to be reflexively made"[29]; a project in which the notion of lifestyle appears fundamental: "in conditions of high modernity, we all not only follow lifestyles, but in an important sense are forced to do so – we have no choice but to choose."[30]

In anthropology, medical practices are considered to be cultural practices that symbolically bring about a specific framework for relations and for decision-making.[31]

We can therefore ask: is autonomy truly an intrinsic dimension of humankind, or is it rooted in a specific cultural vision of the person typical of a particular historical context? Can the procedures of informed consent be seen as ways by which particular cultural assumptions are enacted? And again: is having the patient participate in decision-making a guarantee of his/her best interests?

Without going to remote regions of the world, is the individual truly autonomous even "at home"? In making choices, do we not all take account of a variety of factors, not least those emotionally interwoven in our network of interpersonal relations? Anthropological research shows that the ideal-typical models which underlie decision-making processes are unlikely to take account of the pragmatic rationality which instead guides social actors in their choices.[32]

As shown, for example, in the context of end-of-life choices, people often behave in an apparently contradictory manner, in that they choose what they believe to be the best for their family, and not for themselves, even if they are the first to say that they would advise their loved ones to do otherwise.[33] This is understandable: after receiving terminal diagnoses, patients are often more distressed by the fates of those who will survive them. Having accepted death, they find the thought of the pain of those they will leave behind hard to bear.

Acting in the best interest of the patient, therefore, does not mean merely asking him or her to choose among different therapeutic options generated by diagnostic tests performed by health professionals. It also means engaging in co-construction of the meaning of the illness experience in light of which a choice can be made. This process is not accomplished through informed consent or by mechanically applying bioethical principles; rather, it is a process that must be co-constructed with the patient. It is therefore necessary to create an alliance among health professionals, patients and their families so that they can jointly decide, with their respective competences, after they have reconstructed the failed signification process. Hence a synthesis must be performed between the lived body and the body objectified by the medical sciences through the personal involvement of professional actors and professionalization of the persons concerned with the patient. In this regard, Sally Gadow[34] speaks of 'existential advocacy', i.e. the need for a relational ethic in which healthcare professionals, together with patients and their significant others, engage in this process of reconstructing a meaningful world, in order to guarantee the right of patients to make a choice appropriate to the value attributed to the situation.

Narrative approaches in medical anthropology[35] have pursued precisely this twofold objective: first, to facilitate analysis of the processes of dissolution of the lived world and thereby achieve understanding what a particular experience of suffering means for those involved; second, to promote the active participation of patients in the production of meaning whereby sense is given to an unprecedented form of experience of/in the world.[36]

Whilst anthropological models based on the distinction between disease and illness advocated an approach which examines the views of patients concerning the nature of their suffering, narrative approaches recommend participation in the intersubjective process of constructing the meaning of the experience. Operationally, this translates into a systematic attempt to enable the patient to explore his/her 'conceptions' and thus formulate his/her own perspective. The patient's perspective is therefore not assumed to be 'something' that must be taken into account, or on which to begin negotiations. Rather, it is assumed that the patient's perspective must be produced intersubjectively, and that narratives are the means to do so.

> When members of a society lack the capacity for self-reflection – i.e. when people find it difficult to assess their own dysfunctional practices – they become vulnerable to choosing bad meaning over no meaning.[37]

Sally Gadow highlights, through her research experience, how doctors often resist this approach, on the grounds that opening up to the personal dimensions of suffering not only puts them at risk of burnout but also requires an involvement that may undermine their capacity for professional judgement. But Gadow shows that the opposite is the case: the twofold process of personalizing the professional and professionalizing the personal not only increases the satisfaction of patients, but also that of doctors. In this case, what produces burnout is not so much personal involvement as the distress caused by the opening up to the personal dimensions without knowing how to value them in the therapeutic relationship. If, by contrast, there is a commitment to promoting co-production by the patient of the meaning of his/her disease, not only does the doctor no longer feel the frustration of having to reduce the experience to mere organic processes, but s/he also has the profound satisfaction of having fully done his/her duty.

Narratives are therefore means with which to enhance the patient's agency in meaning production. S/he can thus define the experience of illness, accept the inevitability of the diagnosis, and make choices consistent with the new imperatives imposed by the suffering. Narrative and phenomenological approaches in medical anthropology have made possible a radical rethinking of therapeutic efficacy in terms of developing meanings capable to substantiate a renewed presence in an previously unknown world (also because the transformation experience that we culturally define as 'healing' can never be a return to the initial existential situation).

Generally, in medicine, efficacy is defined in terms of the success of a particular therapeutic intervention. But this is to ignore the fact that other dimensions are involved in defining therapeutic efficacy.[38] The diagnosis itself is a process by which meaning is given to the suffering experience, and it contributes to efficacy not only by identifying the level on which to act therapeutically but also by assisting definition of the meaning of the lived experience of illness. This consideration demonstrates the extent to which the dimension of meaning is crucial in treatment, even when the medical system excludes it from its explicit ideology (as is generally the case in biomedicine). The inability to make sense of our problematic experiences thus emerges as the very source of the crisis because it hampers our capacity for action: where can we go, what can we do, if we do not know what the problem is, if it has no meaning?

It is evident that the symbolic dimensions of efficacy should not be seen as alternatives to the efficacy of biomedicine, for they are always present, even in those areas culturally marked in technical terms. If these symbolic dimensions are always present, and inform even the most reductionist biomedical practices, becoming aware of them creates scope for action otherwise precluded. Medical action perforce involves processes of symbolic production which narrative approaches seek to include within conscious action, with the precise purpose of involving patients in the production of meanings that enable choices to be made. It is necessary to expand the scope of the concept of therapeutic efficacy to encompass not only the possible changes that therapeutic techniques can produce at the anatomical-physiological level, but also the changes in sense relations that must be renegotiated as a result of the dissolution of certainties generated by the crisis of the body in the world.

Given the argument thus far, it is important to acknowledge the constitutive relationship between experience and meaning production whereby is not the communication of information that changes experience, but the production of meaning itself. The recent phenomenological-cultural approaches show that experience is not qualified by the communication of information but by the production of meaning.[39] The participation of patients is therefore essential because it favours conditions that can clarify the key issues at stake in their experience of illness (clarity, as said, that is not necessarily present precisely because of the practical and implicit nature of the cultural processes which are active parts of our experiential and not just linguistic-cognitive dimensions). As the Lancet Report states, competence is about making meaningful relations.[40]

At this level, medical anthropology can be a strong ally of biomedicine. Whilst the latter's techniques can generate significant changes in the somatopsychic organism, anthropology furnishes tools to enhance the symbolic dimensions of the transformation of self through which a person can renegotiate the terms of his/her existence.

It might be objected that medical work leaves little time to invest in the relationship with the patient so as to foster this process of experience elaboration. Again we need to reconfigure the terms of the question: if we consider the therapeutic process as a whole, what medical-anthropological research shows is quite the opposite. Investing in the doctor/patient relationship enhances the overall efficiency of the medical system, as already shown in 1975 by Hampton and colleagues. Put otherwise: investment in symbolic efficacy reduces the overall time required by the therapeutic process because it creates a virtuous synergy between efficacy and efficiency. Obviously, achieving this synergy requires action in regard to both training and the reorganization of services, to the extent that these principles can be implemented in practice.

Put extremely briefly, therefore, acting in the patient's best interest and promoting his/her right to meaning[41] coincides with the promotion of the doctor's best interest and, ultimately, with enhancement of the healthcare system's efficiency.

Accordingly, communication in the doctor/patient relationship should be radically rethought: the issue is no longer being certain that the patient will respond to the information provided by the doctor; the central concern is now to ensure that the patient is able to produce a perspective.

Right to meaning and cultural differences

While the right to meaning is a fundamental dimension of the doctor/patient relationship, it plays a key role also in regard to other therapeutic traditions. In fact, reductionism not only excludes the patient's perspective, it may also delegitimize different views of clinical reality. This issue becomes central in operational terms when promoting the production of meaning of illness with foreign patients, who may interpret their experiences in terms culturally distant from our customary symbolic references.

Distinctive of the therapeutic relationship with foreign patients is the need to reflect explicitly on the dynamics that always occur but do so unconsciously when dealing with patients with whom there is a strong implicit sharing of the assumptions on which our embodied mode of being-in-the-world relies.

Hence, what distinguishes the encounter with foreign patients is the need to reflect explicitly on the symbolic dimensions that are always present in the relationship. The risk is that the scientistic ideology of biomedicine will induce practitioners to construe cultural difference as error, thereby undermining precisely those intersubjective dynamics of co-construction of the meaning of experience discussed above. Once again, a series of dichotomies implicitly shape our practical attitudes: us/others, science/belief, truth/error.

Healthcare services often ask anthropologists for advice on how to deal with foreign patients whose interpretations and behaviours are difficult to reconcile with the clinical rationality of biomedical knowledge. The same applies in the case of healthcare cooperation programmes. The attitudes encountered in these two different contexts are often similar. Cultural difference is regarded as an obstacle to the achievement of therapeutic efficacy, so that efforts in communication are devoted to promote the compliance of foreign patients – or the populations concerned by healthcare cooperation programmes – with the instructions of the biomedical practitioners, but, as in the case of the doctor/patient relationship, communication is still conceived as a one-way process designed to configure users in a manner compatible with the requirements of the practitioners.

At this point, granting the right to meaning can only derive from prior self-reflexive recognition of the cultural nature of Western medical forms, once again not to delegitimize them but to acknowledge their cultural selectivity. Only then can one seriously consider the meanings conveyed by culturally different therapeutic languages and experiences of suffering.

Consider the case of Janice, a 17-year-old Nigerian girl who had illegally immigrated into Italy. Forced into prostitution, she managed to escape and bring charges against her Nigerian procuress and the latter's Italian partner. Social services offered her safe housing and placed her on a protection programme. But shortly after her arrival she was forced to leave the shelter by the other girls, who claimed that she was possessed by a spirit, *Mami wata*. When she was treated at a mental health centre, her illness was diagnosed as a form of psychosis.

When we mechanically adopt medical categories, we also project specific images of the person, of reality, and of knowledge that do not necessarily help us understand the extent and meaning of the patient's suffering. *Mami wata* is a spirit often depicted as a mermaid, although she embodies both genders. She is pale-skinned, adorned with jewels and symbols of abundance, wealth, prosperity. Those wanting to achieve personal fulfilment and economic success may enter into a pact with the spirit, who in return demands loyalty and part of the success achieved through its mediation. The fact that Janice became possessed by this specific spirit precisely when she escaped prostitution is highly significant: now that *Mami wata* was no longer earning, it caused her disorder because the pact had been breached. The spirit had enabled the girl to enter Europe – an icon of success and personal fulfilment – but it no longer participated in the proceeds from her presence in the West (because Janice had stopped making money). Janice's entire migratory project was jeopardised by a failure which also caused her great hardship.

The spirit thus emerges as an embodied interpretative practice, as a bodily technique with which Janice took a critical stance against the social processes in which she was trapped.[42] Her body was an active agent which translated – through its cultural moulding – the painful relationship between the person and the world. From this perspective, not only is it not possible to understand Janice's possession by using the language of psychopathology, but neither can therapeutic action produce an appropriate transformation of her experience.

In cases like this, the phenomenological-cultural approach is designed precisely to engage the patient in exploration of conceptions configured in terms of inter-cultural co-construction of the meaning of his/her experience, with the consequence that both the diagnosis and the therapy are reformulated. If the sole aim was to make Janice's perspective explicit, what else can be said except that she was possessed by a spirit? Instead, encouraging her participation in an intercultural process of dialogue-based exploration of her experience yielded an interpretation that otherwise would never have entered the sphere of language, and therefore of explicit reflection. It would have remained confined to the lived dimensions of the experience of suffering.

We now turn to a different context – that of healthcare cooperation – which illustrates how communication may fail to achieve its purpose. During personal research in North-West Cameroon, I found that AIDS was often interpreted as a form of State witchcraft.[43] The national and international agencies engaged in combating AIDS in the years before the advent of anti-retroviral drugs – as part of the World Health Organization's Global Programme on AIDS – dismissed these interpretations as stemming from traditional local beliefs which replaced the correct interpretation of the disease in biomedical terms. Because a therapeutic option was not available at the time, the only means identified by WHO to combat the epidemic was prevention through information campaigns. Once again, the core of these initiatives consisted of the cultural assumptions typical of biomedical reductionism. The goal was to provide accurate information on the nature and transmission of HIV in order to engender change in sexual behaviour. This strategy was evidently based on a rationalist model of human action that prioritizes the individual level: behaviour is merely the result of a cost/benefit calculation that, once the correct information has been provided, induces those concerned to take appropriate action.

On the one hand, these initiatives viewed the local culture as a risk factor; on the other, they endeavoured to change individual sexual behaviour without considering the decisive socio-economic and political factors, both local and global, restricting the capacity for individual action.

On closer analysis, however, the view of AIDS as a form of witchcraft can be considered an interpretation that identifies economic inequalities as the cause of the epidemic. Use of the discourse on witchcraft to account for the AIDS epidemic was rooted in local beliefs that power is often obtained by unlawful means. In a context of widespread poverty, the accumulation of wealth and success by some is conceived as appropriation to the detriment of others. Hence local discourses on witchcraft were interpretative practices with which to explain social inequalities and power asymmetries. Numerous authors have highlighted that new conceptions of witchcraft have integrated the mysteries of the market economy into their representations in order to explain the growing inequalities that it produces. It is for this reason that in Cameroon, like elsewhere in Africa, modernity and witchcraft seem closely intertwined.[44]

Despite the cultural assumptions embedded in international and local prevention protocols, the interpretation of AIDS in terms of witchcraft does not appear to be a form of denial or lack of understanding. On the contrary, it emerges as a culturally connoted discourse which points to the institutional and political processes deemed responsible for the inequalities that expose the underprivileged to life-threatening risks, not least the risk of AIDS.

It is therefore evident that if communication does not adopt this self-reflexive strategy, it will never be able to intercept local needs. Knowing how to frame medical categories in the anthropological perspective is thus the first step in granting the right to meaning and forming a dialogue-based relationship, in which difference is not denial of truth, but a source of knowledge to be investigated in order to understand what is being talked about when it is claimed that AIDS is a form of witchcraft. Only then can we understand what we cannot implicitly share at the experiential level. We realize that local beliefs are sensible and consistent with those notions that identify precisely in the social determinants of health the main mechanisms of HIV contagion in sub-Saharan Africa.[45]

Once again, illness narratives can be useful for understanding in what sense-making scenarios experience becomes significant. In other words, it is necessary to determine how social experience is culturally moulded in the implicit immediacy of lived experience. The aim is therefore to enable patients to place themselves in a web of sense and provide an account which, though always partial, revisable and processual, has the advantage of translating immediacy into terms that are communicable, discursive and manipulable in the doctor/patient relationship.

In order to understand what is involved in the experience of patients whose symbolic referents (implicit and explicit) are different from ours, we must necessarily explore the cultural forms through which experience is defined. To do so, we cannot rely on typical cultural models (Moroccans believe that, Nigerians think that, Italians ...). We must instead conduct inter-subjective exploration of what scenarios of collective sense-making emerge as significant.

In short, it must be assumed that cultural differences cannot be understood solely in terms of different ways to conceive reality, but rather in terms of different ways to experience reality. Again, it will certainly not be communication understood as the transmission of information which engenders change in the behaviour or experience of patients, but rather active participation by the latter in the process of meaning production. Yet this investment will not necessarily be sufficient to satisfy patients' health needs, as we shall see in the next section.

Beyond the right to meaning: illness as a social process

The two cases described above – possession by *Mami wata*, and the witchcraft-based interpretation of AIDS in N.W. Cameroon – evidence that biomedicine, through its reductionism, also eliminates the socio-economic dimensions of illness, with the consequence that promotion of the right to meaning is not sufficient on its own. The Global Programme on AIDS failed not only because it tended to individualize the social processes of the disease distribution and transmission (depoliticizing them), but also because it neglected the dynamics (not only individual but also collective, not only cultural but also economic, social and political) that produce contexts of risk. By blaming the latter on the incorrect beliefs of social actors (to be modified through the communication of biomedical information), the programme produced a view of the local culture itself as a risk factor. It thus failed to grasp the decisive socio-economic and political forces, both local and global, that form the context of individual action.

As a well-established body of anthropological literature has shown, the use of sexual-economic exchange is not to be understood as a product of local traditional beliefs, but rather as the result of a limitation on people's capacity for action.[46] Consequently, AIDS is often associated with the individual embodiment, at the biological level, of structural violence: that is, the kind of violence produced by forms of social organization characterized by profound inequalities. This is a silent violence which affects the lives of the persons occupying the most marginal segments of those social structures and which manifests itself in very different outcomes: infectious diseases, malnutrition, high mortality rates, low life expectancy at birth, etc. If structural violence penetrates the body by restricting people's agency, then it is by empowering the latter, not by changing their behaviour, that action can be taken to halt the spread of AIDS. In fact, socio-economic inequalities produce suffering not only by limiting access to services, but also by contributing to the spread and onset of diseases. We may consequently speak of outright 'pathologies of power,'[47] of which biomedicine captures the individual effects, the embodied outcomes, through its reductionist language, but does not shed light on the process that constitutes the broader reality.

Put otherwise: understanding that describing AIDS in terms of a form of witchcraft is an accusation against inequalities does not suffice if action is not then taken to promote socio-economic rights. Also in the case of Janice, having understood that her experience of possession represented a cultural practice, an embodied critique of her life circumstances, could not transform the experience unless action was taken to enhance her capacity to renegotiate the terms of her social existence. It is evident that it is not enough to recast communication in terms of participation in the production of the meaning of reality if one does not also act on the social circumstances in which people act and live.

The difficulties that foreign patients often have in complying with therapeutic instructions do not depend on their cultural beliefs, but rather on dynamics due to their social precariousness, and the economic and legal difficulties of their lives and, therefore, ultimately, on the forms of legal and societal acceptance that we afford them.[48]

An intercultural perspective committed to promoting the patient's production of the meaning of his/her illness can reveal relevant dynamics requiring kinds of action and services difficult to predict if the focus is exclusively on the anatomical-physiological dimensions of experience.

Once again, we may refer to the concept of efficacy: in the case of Janice, reactivation of her migratory project through employment placated the spirit harassing her. In the case of AIDS, in many areas of sub-Saharan Africa, forms of empowerment intended to promote socio-economic rights, such as micro-credit for women's associations, have enhanced people's capacity to negotiate the terms of their sexual relationships, and more generally of their social existence, with a significant impact in combating the spread of AIDS.[49]

Conclusion

Whilst granting the right to meaning is not enough, neither is the opposite. If we act with the conviction that we know what is in the best interest of others (patients, foreign or otherwise, communities subject to health cooperation progammes, etc.) because we are certain of the universal validity of our cultural categories, we risk promoting actions that are useless or even harmful.

Accordingly, doctor/patient communication should be rethought in terms of promoting the right to meaning through the participation of patients in producing the sense of their histories. This will furnish the basis for understanding what resources should be activated to transform experience.

If illness arises from a complex social process of which biomedicine grasps the individual dimensions, the efficacy of its action on that end product is likely to be limited or thwarted without adequate action to promote the transformation of experience.

The concept of effectiveness is thus recast not only in terms of the possible anatomical – physiological changes that biomedical techniques can achieve; and not only in terms of the changes in the symbolic interpretation of experience that the right to meaning can promote. It is recast also in terms of transformation of the patient's social relationships. In the anthropological understanding, health and wellbeing are cultural constructs, but they must be socially generated.

In other words, working on the product without questioning the process that has generated it means that the most efficient action will not necessarily be effective.

Rethinking doctor/patient communication as co-construction of the meaning of clinical reality can thus provide the basis for the more efficient determination of the resources necessary to promote the right to health, not only by having the patient's best interest coincide with that of the doctor, but also by enhancing the entire therapeutic process.

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Chapter Six

How to improve the doctor-patient relationship: the role of the symptoms and food diary

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Introduction

The creation and maintenance of a relationship between the doctor – and more generally the health professional – and the patient is of crucial therapeutic importance, and particularly so in the management of chronic diseases. In fact, as shown by substantially all the chapters in this book, despite change in the historical contexts of this relationship and in the roles and features of its protagonists (health professionals, doctors, patients/citizens/users, decision-makers, etc.), the long-term efficacy of any therapeutic strategy revolves around the strength and duration of the doctor-patient relationship. Confirmation of this dynamic is provided by the results of a recent meta-analysis showing that achievement of an optimal patient-doctor relationship favourably conditions the patient's clinical outcome.[1] Like all relationships that arise from an urgent need to solve a problem – which most often involves not only the patient's physical sphere but the emotional, social, and relational one as well, and also the family environment – establishment of the doctor-patient dialogue can occur in successive stages which follow a path that may be linear, but also circular as stages already experienced are repeated.

Acquiring the patient's history is one of the most significant phases of the doctor-patient relationship, because its full reconstruction can significantly influence all subsequent stages of the care, and therefore its final outcome. The patient should recount his or her history as a whole, and not just experiences correlated with the symptoms; and the doctor should participate by actively eliciting the patient's history. In everyday practice, however, this phase does not always come about in the manner required to create an empathetic doctor-patient relationship, and the dialogue is restricted to the collection and assembly of clinical information, sequences of symptoms and the results of biochemical and instrumental tests. There may be diverse reasons for the failure to achieve the requisite communication, including the doctor's inability/unwillingness to listen, difficulties of expression, or, more generally, the patient's inability to provide the doctor with a coherent and complete account. In most public healthcare facilities, the duration of a medical examination is between ten and thirty minutes. It is therefore likely that the doctor has little time to listen and will cut the patient's narrative short.[2] The practical outcome – as reported by a survey on family doctors – is that 15 to 25 percent of patients express disappointment with the quality of the relational and communicative relationship with their doctors.[3] Further evidence with which to interpret this phenomenon is provided by analysis of the context in which the doctor-patient dialogue takes place. It is most often characterized by hierarchies of concerns and priorities that differ between the two protagonists: strictly clinical for the doctor (identifying the causes of the illness, interpreting laboratory or instrumental data, etc.); eminently existential for the patient (impact on his or her quality of life, relationships, efficiency at work, etc.). In fact, the sequence in which patients describe their symptoms is often unrelated to their objective severity but instead follows a subjective hierarchy of importance (specific symptoms, their intensity and sequence, their relation with further symptoms, as well as with everyday events, etc.).

The diary as a communication tool

A tool frequently used to improve the flow of information from the patient to the doctor is a diary in which the patient records his or her symptoms. A diary of this kind can be not only a means of data collection but also an item of key importance in construction of the doctor-patient relationship.

There are various types of diaries, from simple collections of symptoms to accounts of the patient's history, and also different ways to compile them. Moreover, the purposes may be different as well. In fact, diaries are frequently used in controlled clinical studies to assess, and standardize, the effects of pharmacological treatments or therapeutic strategies on specific symptoms. Likewise, they are commonly used in population studies to measure the distribution within the population evaluated of specific clinical features and to record their trends over time. In these cases, preferential use is made of standardized and validated questionnaires. The main criticism brought against the use of patient diaries concerns the possible development of bias – particularly recall bias – given that the patient may not remember the exact sequence and intensity of the symptoms studied, and therefore report them incompletely.[4] Also documented is the possibility that, if the diary is not compiled in regular and timely manner, the patient may complete it just prior to the check-up or examination, with the greater likelihood that he or she will report non-real data due to partial recall.[5] In fact, there are conflicting findings in the literature on the usefulness of the patient diary, but the conflict is probably due to the diversity of the studies and on the fact that most of them use predefined questionnaires, not free writing by the patient. Studies on healthy subjects document that the diary may amplify the symptoms in terms of both frequency and intensity.[6] There is also an extensive debate on the relative merits of paper-based and electronic diaries, with some studies suggesting that the latter can ensure greater and more prolonged compliance by the patient,[7] whilst other studies do not document significant differences.[8]

In order to privilege the doctor-patient relationship with respect to the methodological rigour of a controlled study, giving patients the opportunity to recount their histories is indubitably important. In fact, it has been shown that writing about events deemed significant from the emotional point of view (narrative writing) can significantly improve a patient's quality of life and symptoms.[9] Narrative writing has been used for different pathological conditions: depression, rheumatoid arthritis, hypertension, chronic pain, chronic infections (HIV), as well as clinical conditions characterized by prolonged hospitalization.[10] Some authors[11] have suggested that the use of narrative writing can also have economic benefits deriving from factors like the less frequent use of social services or the reduced duration of hospitalization. However, the mechanisms by which narrative writing improves the clinical picture have not been identified, since different levels (cognitive, emotional, social, biological) are involved; consequently, an all-encompassing theory is difficult to formulate. Furthermore, it has not been determined why the beneficial results are protracted in time (is it possible that the improvement in the clinical condition reduces the patient's attention to the symptom?). However there is no overall agreement, since a recent meta-analysis has shown that narrative writing reduces the utilization of healthcare facilities by healthy subjects, but not by diseased ones.[12]

The diary in functional gastrointestinal diseases

A field in which the diary (understood as a means of communication between the patient and the doctor) acquires particular importance is that of functional gastroenterological diseases. This term denotes clinical conditions – in particular irritable bowel syndrome – whose symptoms are chronic or recurrent abdominal pain or discomfort and altered bowel habit, but in the absence of other pathologically-based disorders.[13] These are very frequent disorders (representing up to 50% of gastroenterological examinations)[14] characterized by low mortality but also, due to their great frequency, high morbidity. They are diseases that impact negatively on the patient's quality of life and entail high healthcare costs, both direct (examinations, diagnostic tests, medications) and indirect (absence from work, etc.). They are pathologies for which there is no biological marker to use in performing the diagnosis.[15] The latter, in fact, is often difficult and almost always consists in a diagnosis by exclusion reached after organic pathologies have been ruled out.[16] In order to reduce the diagnostic complexity, the scientific community has identified clinical signs (those conventionally termed the Rome III criteria: presence of abdominal pain which disappears with defecation, associated with a change in the shape of the stools and in the frequency of defecation), whose recognition allows diagnosis of a functional disease.[17] The diagnostic difficulties, and therefore the need for objective and shared criteria for diagnosis, concern both specialist medicine and primary care.[18] Moreover, acquiring precise information on the characteristics of the symptoms is crucial, not only for performing the diagnosis and identifying the best therapeutic strategy for the individual patient, but also for monitoring the treatment's efficacy. In regard to the latter, although the Rome III criteria are useful for diagnosis, they are not so for patient follow-up.[19] The sometimes difficult diagnostic pathway also carries the strong risk that the doctor will adopt a defensive attitude. He or she may issue a excessive number of referral prescriptions for fear of getting the diagnosis wrong. Conversely, the doctor may underestimate the seriousness of the case; an error that may lead to non-recognition of even severe diseases. All this explains the need for clinical management strategies whose success is based mainly on narrative by the patient and listening by the doctor; both of these are key elements in the progressive construction of the empathic relationship between doctor and patient that enables them to share the diagnostic-therapeutic work-up.

As in the case of other functional disorders, so for those involving the digestive system, creation of the doctor-patient relationship is not always straightforward. There are numerous reasons why it is difficult to accomplish. Patients with functional pathologies frequently deny the functional component of their symptoms;[20] their satisfaction with the relationship with the doctor is closely dependent on their expectations, so that, as reported by some authors,[21] differences may arise between doctor and patient about the nature of the clinical problem. A study has shown that the specialist underestimates the number and severity of the patient's symptoms (43% and 41%, respectively), and that the patient and the specialist may disagree on the best treatment for a given symptom.[22] Patients with a functional pathology may perceive, even if mistakenly, the doctor as hostile and unsympathetic,[23] whilst the doctor may become intolerant of such patients. Systematic reviews of the literature tend to confirm that the available evidence supports the hypothesis that patients with functional pathologies are dissatisfied with their general practitioners (who are their first medical referents).[24] This is contrary to the widely-held belief that a strong doctor-patient relationship is of central importance for management of patients with functional disorders.[25]

As said, the diary is a useful tool for constructing the doctor-patient relationship; and various tools, such as interviews, self-administered questionnaires, and diaries, have been proposed for the management of patients with functional gastrointestinal disease. The current evidence does not unequivocally show which is the best way to recount and collect the symptoms of patients with functional gastrointestinal disease. However, it is agreed that a tool collecting the symptoms experienced by the patient is necessary, given that the symptoms of irritable bowel syndrome are often episodic in nature, so that only a prolonged account can make their measurement possible. According to some authors, use of a paper-based diary rather than an electronic one induces increased recall relatively to the pain and frequency of defecation, which, as said, are important elements in the diagnosis of irritable bowel syndrome.[26] Other authors instead find a rather good match between paper and electronic diaries.[27] For that matter, research data suggest that increased recall of daily symptoms and greater perception of symptom severity can also be produced by healthy subjects,[28] although the study concerned had some limitations: for instance, it was conducted only on women. It has also been suggested that the two methods – paper-based and electronic – used to collect symptoms differ from each other in that they may measure different phenomena.[29] Nevertheless, the diary seems more accurate than a structured interview or questionnaire in identifying the symptoms of functional diseases.[30] In any case, international guidelines[31] suggest using the patient's diary to perform the diagnosis and to assess the patient's compliance with the agreed therapeutic strategies and their efficacy. 'Narrative writing' has also been used in the case of patients with functional pathology.[32] Halpert et al. performed an online study where the enrolled subjects were requested to write for 30 minutes a day for 4 consecutive days about their deep thoughts, emotions, and beliefs about the disease and their perception of its effects. Comparison between those who completed the study (writers) and those who did not (non-writers) showed that the severity of the disease was reduced among the former and that awareness of the disease improved. The authors also suggested use of a tool that records lifestyle habits (sleep/wakefulness, dietary habits, etc.) together with the symptoms (across 24 hours, and over the week). A further argument in favour of the clinical utility of the diary is the observation that many patients with functional disease believe that there is a relationship between their symptoms and food intake, or that the characteristics of their symptoms are influenced by physiological conditions such as sleep, defecation, etc. In fact, it has been documented that patients with more intense symptoms and whose clinical situation impacts more strongly on their quality of life more frequently recount symptoms relating to allergies/food intolerances.[33] Demonstration of the real existence of this association is important, because there is evidence that psychological factors (anxiety and depression) are frequently present in subjects who report symptoms related to food hypersensitivity and may influence the clinical picture.[34]

The food diary

It therefore seems evident that in clinical practice, in regard to patients in general, and those with functional pathologies in particular, it is necessary to use tools able to record prospectively both their symptoms and their dietary habits. The food diary on its own is a tool widely used, particularly for eating disorders.[35] It is an integral part of the cognitive-behavioural work-up which is the most effective therapeutic strategy for these disorders, and its fundamental purpose is to provide information on the patient’s eating habits and then, once the nutritional errors have been identified, allow change in eating behaviour. In most cases, the food diary consists in the prospective recording of food and drink intake, for a period of time usually lasting between 3 and 7 days,[36] although it may be extended to twenty days. The diary is the means by which the patient reports the quality and quantity of the food that he or she consumes, so that it furnishes a useful instrument of external control. Its use in eating disorders has been advocated by Wilson and Fairnburn,[37] who propose it as the technique with which to treat bulimia nervosa. According to these authors, the food diary should be carefully updated by the patient as soon as he or she has eaten food, reporting not only the quality and quantity of the foodstuffs consumed, but also the time, place, any sensation of having over-eaten, behavioural consequences (vomiting, use of laxatives, diuretics, physical activity, fasting), and cognitive, emotional and relational aspects. The quantities consumed can be assessed by using food servings (a cup, a glass, a teaspoon, a slice of bread, etc.) ('simple diary') or by weighing food ('weight diary'). The recommendations on keeping a diary emphasise that it should be written up immediately after the intake of food and not at the end of the day. The weight diary is the reference technique for evaluation of eating habits, but it involves a high degree of interference in the patient's life and requires a significant degree of cooperation. Sometimes patients compile it with scant interest because they regard it as a rigid and punitive control; or they treat it as a 'shopping list' of what they have eaten and hastily update it in the evening or just before the session. But the diary is essential for the success of the therapeutic programme, although it is obviously only one component of the overall therapeutic strategy.

Since the most important factor in changing attitudes towards food is the patient's self-awareness of his/her behaviour,[38] the patient must take daily notes on food intake, the events influencing it, and the symptoms that it induces or is believed to induce. The diary is therefore a means to know the patient's cognitive, emotional and behavioural, as well as dietary, characteristics. The diary is initially well regarded by patients, and they will use it properly if it is proposed as a means to evaluate the relationship among what they eat, think and feel. Over time, the diary serves to monitor the patient's progress or difficulties in dietary, emotional and cognitive terms. In clinical practice, it is a valuable tool with which to determine the patient's ability to manage the food plan, to investigate the psycho-social correlates of food intake, to compare the changes in food choices compatible with remission and improvement of symptoms.[39] Hence, in order to define a shared and effective diagnostic-therapeutic pathway, it is important to ask patients with functional gastrointestinal disorders – particularly in regard to symptoms correlated with food intake – to compile a diary describing not just their symptoms but also their eating habits, as strongly recommended by scientific societies.[40]

The food and symptoms diary: our experience

Our experience – performed at a gastroenterology unit of the S.Orsola Hospital in Bologna – in use of the food and symptoms diary in clinical practice began in 2010, when we designed a diagnostic-therapeutic work-up for patients with functional gastrointestinal disorders. The clinic treats patients sent from the specialist out-patient or gastroenterology departments with diagnoses of functional disease. The work-up begins with a request by the doctor – after a gastroenterological examination in which a functional disease is diagnosed – that the patient keep a diary for at least ten days and log the food eaten, also stating the time of day or night. The patient should also note any appearance/recurrence of symptoms, describing their duration and intensity, and the conditions that trigger them, in particular the eating of specific foods. A further component of the diary is description of the quality of physiological functions like as sleep and defecation, and their possible relations with the symptoms and diet. The patient is asked to keep the diary for at least ten days. This time span will include two weekends, which are times when eating habits and lifestyle may change. The patient is free to compile his or her diary either on paper or electronically; and may send it by email or fax, or deliver it by hand. The patient is then assessed by the dietician using a food investigation. The diary is subsequently analysed jointly by the gastroenterologist and dietician, who supplement it with data from the clinical examination and the food investigation. The work-up concludes with a final examination, during which the patient, the doctor and the dietician jointly decide the strategy (pharmacological and/or nutritional and/or behavioural) appropriate to the specific clinical picture. The patient remains in contact with the professionals, reporting the evolution of his or her disorder. If it is deemed necessary, the diary is repeated.

Since 2010 we have collected 258 food diaries compiled by 88 males and 170 females, with an average age of 55 (range: 18-87 years old). As stated above, all the patients had been diagnosed with functional gastroenterological disease according to the Rome III criteria.[41] The patients' interpretations of how they should compile their diaries as accounts of their eating habits and symptoms were highly diversified. As regards the formal mode of compilation, some patients preferred to compile their diary in electronic form, using an Excel file or a Word table; others sent it as an email attachment; others used notebooks; others wrote on loose sheets of paper; and yet others made notes in their personal diaries. Moreover, eating habits and symptoms were described in two different ways: either concise or detailed. A further feature distinguishing the interpretation and compilation of the patients' diaries was how dietary habits and symptoms were logged: either both were reported (as requested during the first examination) or only one of the two (i.e. only symptoms or only eating habits). Of the 258 diaries analysed, 158 (61%) had been compiled electronically and 90 (39%) on paper. Moreover, 32% of the former were compiled in detail and 68% only concisely. As regards the latter, the percentages were respectively 26% and 74%. For both modes of compilation, the concise diaries contained only a description of the food eaten, but nothing about symptoms, even though these had been reported by the patient during the interviews with both the doctor and the dietician.

As said, one of the purposes of the diary was to facilitate identification of a possible cause-effect relationship between the genesis of symptoms and the consumption of certain foods. For this reason, the patient was requested to report all the food eaten and any symptoms. Interestingly, although all the patients had been given the same information about the purpose of their diaries, they were frequently very different from each other, in particular from a formal point of view. This suggests that the patients interpreted the food and symptoms diary's purpose differently. Indeed, some patients merely listed schematically, and in a certain sense anonymously and impersonally, the items of food eaten, with perhaps a daily summary of symptoms. Others produced diaries characterized by detailed accounts, sometimes with interpretations of symptoms, their relation with food and physiological functions (sleep/wakefulness, defecation, etc.). In one case, the diary consisted of a meticulous collection of the labels of the food products consumed by the patient, with notates concerning the onset of symptoms related to the specific food eaten (Figure 1). The labels were handed over during check-ups to receive advice on bromatological composition, i.e. the carbohydrate, protein and fat content of foods or their nutritional quality. The objective was to help identify ingredients involved in the genesis of symptoms, which in some cases could vary according to the brand of the product, probably because of the presence of different additives. In this case, as in others, this complex process proved very useful, because it made it possible to identify the components able to trigger the symptoms, and thus prevent the onset of the latter.

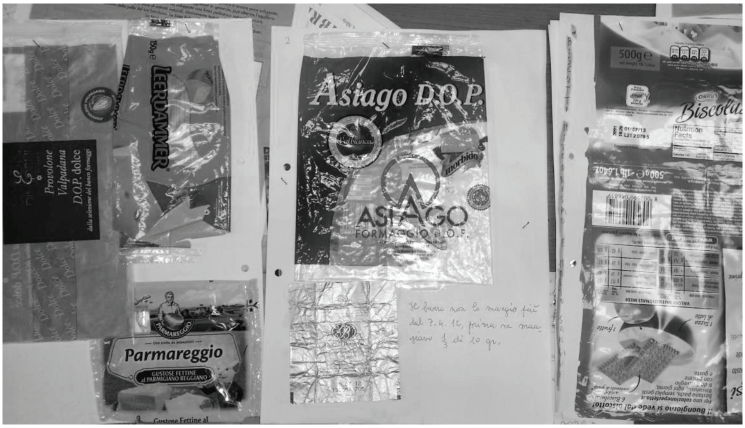


Figure 1. Example of a diary. The patient performed a sort of collage from the labels of the products consumed, with notes on the symptoms possible caused by a specific type of food.

Moreover, as regards the formal mode of compiling the 'concise' diaries, these often did not report the amounts of food eaten; nor did they give detailed descriptions of symptoms – indeed, these were entirely absent in some diaries. As regards the detailed diaries, some of them gave precise descriptions of the dishes eaten and the symptoms present; others referred only to the symptoms experienced or only to the food consumed. Some of these diaries were compiled with an almost maniacal attention to detail. Particularly significant in this respect was the diary of a patient which began with a meticulous account of her diseases since birth, food intolerances diagnosed (or presumed), descriptions of skin reactions to drugs, before moving to description of her everyday diet, symptoms, moods in different situations during the day, physical activity, and types of bowel movement. These features were found in around 20% of the diaries classified as detailed, both paper-based and electronic. The compilation mode (detailed or concise) did not seem related to the age, education level, or gender of the patients, nor to the severity and mode of onset of symptoms. Analysis of the diaries showed that the detailed ones were more frequently kept by patients with a greater perception/fear of the severity of their symptoms. In these cases, the high level of detail seems to have been both a sort of request by the patient for professional attention, and a way to externalize his or her experience, thereby reducing anxiety. As regards differences in the use of paper and electronic diaries, the latter were preferred by patients who worked and were therefore probably accustomed to using a computer, while paper diaries were preferred by retirees or housewives.

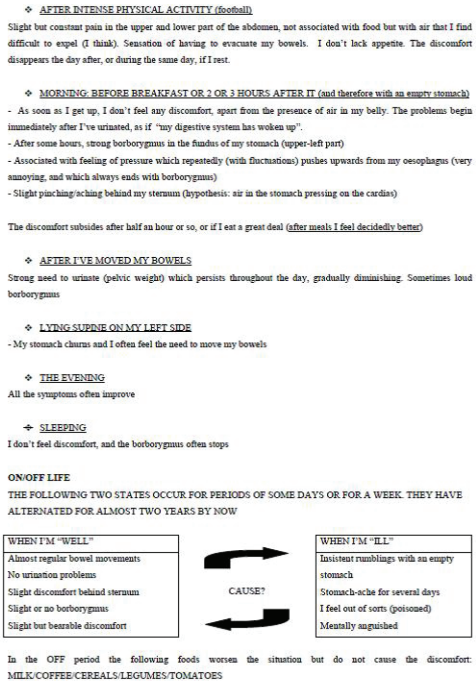
In some cases, compilation of the diary, and its subsequent joint analysis, made it possible to exclude a causal correlation between symptoms and food eaten. This required further investigation by means of laboratory and/or instrumental diagnostic tests, which had been excluded in the first phase, either because they had already been performed but with negative results, or because they had been deemed unnecessary given the symptoms reported. This further investigation, and repetition of the diary, led to the detection of organic diseases (albeit in their initial stages), such as intestinal malabsorption syndrome or polyposis of the colon, and therefore made it possible to devise the correct therapeutic strategy. In the case of two patients, reading their diaries revealed that their symptoms were related to body dissatisfaction not externalized during the preliminary interviews. Consequently, the therapeutic work-up initially characterized by a close symptom-food relationship was changed to produce an overall improvement in nutrition and lifestyle.

Overall analysis of the experience evidenced that, over the years, the patients took increasing care when compiling their food diaries. In fact, initially more frequent were diaries containing merely long lists of foods, with no mention of portions, nor descriptions of symptoms. Thereafter, the diaries gave more details on the units of measurement, identifying portions or grams, symptoms, and/or sometimes even the sensations aroused by eating the meal or the onset of a particular symptom. This change may also have been partly due to a gradual improvement in the relational skills of the health professionals in dealing with their patients.

Regardless of the type of patient, the reliability of the diaries was generally very high, probably because the patients became increasingly aware of the importance of accuracy for targeted management of their symptoms. By contrast, a similar quali/quantitative correspondence was not found in many patients with obesity. This was presumably due to the fact that pain is frequently moderate, if not absent, for these patients, so that the extent of the clinical problem (obesity as a risk factor for numerous gastrointestinal disorders, as well as others) was not perceived by the patient, with the consequence that his or her motivation to change was very weak. In most cases, the diary was proposed at the beginning of the pathway, and it proved sufficiently informative to frame and manage the clinical problem. Once the nutritional strategy had been jointly decided, it was monitored during subsequent examinations. In the majority of cases, it was not necessary to repeat the diary, since the food investigation proved sufficient to assess the achievement, or otherwise, of the change objectives set. Instead, repetition of the diary was necessary both in cases where further monitoring was essential because there had been no significant remission of the symptoms and in those where there emerged aspects which required further nutrition recommendations or changes (e.g. the need to start an exclusion diet in the presence of documented allergies or intolerances). It was also necessary to resume the diary when it was not possible to identify a causal relationship between the patient's symptoms and eating habits through analysis of his or her first diary. In these cases, it was indispensable to identify an association between the symptoms and a particular food or its ingredients (for example, a suspected pathology associated with gluten or other food allergies and intolerances). Continuing to compile the diary proved fruitful in different conditions, such as when the patient knew that it was useful support for the shared nutritional work-up and when the diary represented for the patient a guide to actively reporting of the ingredients of products. The ultimate purpose of the diary was to increase the patient's compliance with the change.

The diary also proved valuable for the doctor when the food/symptom relation did not appear convincing and it was necessary to improve the diagnostic work-up with further analyses. Monitoring proved necessary for eleven patients. In the sample analysed, five patients asked on their own initiative to continue monitoring their behaviour. In these cases, the patients continued to keep diaries for different periods, some for a few months, some for more than a year. Several factors may have been responsible for this choice; we can assume a normative influence (in fact, it can be argued that compilation of the diary assumed the nature of a self-imposed rule which positively influenced the patient's behaviour). The desire to change, to improve understanding of their behaviour by the doctor or dietician, to feel psychologically more cared for and supported, and to foster self-knowledge suggest behaviour subject to the effect of social desirability. A significant example is provided by the diary of a young student with gastroesophageal reflux disorder and gastric symptoms which were important and persistent over time despite repeated and diverse therapies. The sharing of a nutritional scheme and compilation of the diary, with its significance as substantial control over compliance with the nutritional advice received, resulted in reduction of the disorder, but not its complete disappearance. Figure 2 shows an excerpt from the patient's diary in which he records the symptoms in detail, their possible triggering factors, but also their possible interpretation. The page ends with a final question addressed to the doctor and the dietitian: "When I'm well - when I'm ill: what's the cause?" Compilation of the diary continued for a long time because it served the patient to increase control over both qualitative choices and management of the distribution of food across the day, so that he could correlate symptoms with behaviour. The incomplete remission of the symptom and the failure to identify a cause-effect relationship then induced the patient to ask for psychological support to be added to the nutrition strategy.

Repetition of the diary was requested by the doctor in six other cases in which the change of nutritional and behavioural habits had not been matched by an improvement in the clinical picture. For example, a patient previously treated by other healthcare facilities without substantial improvement in her condition, and who presented constant negativity in all laboratory and instrument examinations, was asked to continue to log what she ate and her symptoms. The reason for this repetition was that, at each consultation, changes were made to the quality of the woman's diet in order to determine what food or ingredient might be responsible for her symptoms. In the absence of significant results, she began a drug therapy which produced positive outcomes. The woman had always carefully compiled her diary, on the one hand in order to find a solution, and on the other to demonstrate her compliance with the diet, but to no avail.



❖ AFTER INTENSE PHYSICAL ACTIVITY (football)

Slight but constant pain in the upper and lower part of the abdomen, not associated with food but with air that I find difficult to expel (I think). Sensation of having to evacuate my bowels. I don't lack appetite. The discomfort disappears the day after, or during the same day, if I rest.

❖ MORNING: BEFORE BREAKFAST OR 2 OR 3 HOURS AFTER IT (and therefore with an empty stomach)

- As soon as I get up, I don't feel any discomfort, apart from the presence of air in my belly. The problems begin immediately after I've urinated, as if "my digestive system has woken up".
- After some hours, strong borborygmus in the fundus of my stomach (upper-left part)
- Associated with feeling of pressure which repeatedly (with fluctuations) pushes upwards from my oesophagus (very annoying, and which always ends with borborygmus)
- Slight pinching/aching behind my sternum (hypothesis: air in the stomach pressing on the cardias)

The discomfort subsides after half an hour or so, or if I eat a great deal (after meals I feel decidedly better)

❖ AFTER I'VE MOVED MY BOWELS

Strong need to urinate (pelvic weight) which persists throughout the day, gradually diminishing. Sometimes loud borborygmus

❖ LYING SUPINE ON MY LEFT SIDE

- My stomach churns and I often feel the need to move my bowels

❖ THE EVENING

All the symptoms often improve

❖ SLEEPING

I don't feel discomfort, and the borborygmus often stops

ON/OFF LIFE

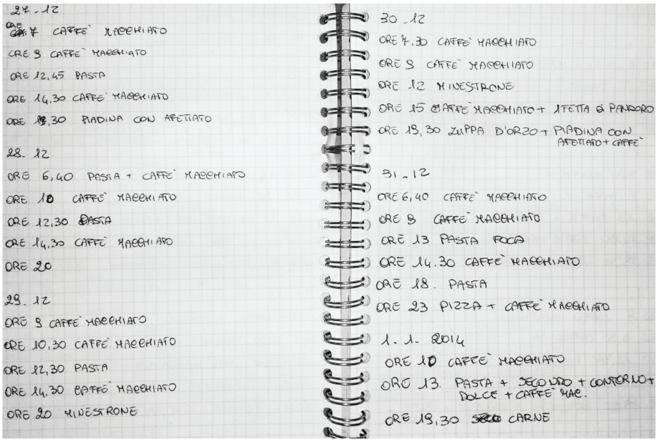
THE FOLLOWING TWO STATES OCCUR FOR PERIODS OF SOME DAYS OR FOR A WEEK. THEY HAVE ALTERNATED FOR ALMOST TWO YEARS BY NOW

WHEN I'M "WELL"		WHEN I'M "ILL"
Almost regular bowel movements		Insistent rumblings with an empty stomach
No urination problems	CAUSE?	Stomach-ache for several days
Slight discomfort behind sternum		I feel out of sorts (poisoned)
Slight or no borborygmus		Mentally anguished
Slight but bearable discomfort		

In the OFF period the following foods worsen the situation but do not cause the discomfort: MILK/COFFEE/CEREALS/LEGUMES/TOMATOES

Figure 2 Example of a diary. The patient reports symptoms and foods, concluding with a diagnostic note.

Two other clinical stories show how a patient's behaviour may vary according to what he or she actually wants, or does not want. In one case, the patient wrote in a notebook, with punctuality and diligence, everything that she had consumed during the day. The diary was kept by the patient for several months, but it always reported the same foods (Figure 3) taken repetitively and without changing their quality or quantity, even though the woman had been advised at the monthly meetings to diversify her eating habits. Moreover, the diary logged only the food eaten, not the woman's symptoms, which were instead reported verbally to the doctors. The patient had never cancelled an appointment, but on the other hand she had never followed the advice given to her. After several meetings, it emerged that the core problem was the woman's fear of putting on weight, which prevented any change and made abdominal pain of secondary importance. The woman's fear of gaining weight explained the monotony of her diet. In this case, the diary did not help the woman to



27 - 12
ORE 7 CAFFE' MACCHIATO
ORE 9 CAFFE' MACCHIATO
ORE 12,45 PASTA
ORE 14,30 CAFFE' MACCHIATO
ORE 19,30 PIADINA CON AFETTATO

28. 12
ORE 6,40 PASTA + CAFFE' MACCHIATO
ORE 10 CAFFE' MACCHIATO
ORE 12,30 PASTA
ORE 14,30 CAFFE' MACCHIATO
ORE 20

29. 12
ORE 9 CAFFE' MACCHIATO
ORE 10,30 CAFFE' MACCHIATO
ORE 12,30 PASTA
ORE 14,30 CAFFE' MACCHIATO
ORE 20 MINESTRONE

30 - 12
ORE 7,30 CAFFE' MACCHIATO
ORE 9 CAFFE' MACCHIATO
ORE 12 MINESTRONE
ORE 15 CAFFE' MACCHIATO + 1 FETTA DI PANDORO
ORE 19,30 ZUPPA D'ORZO + PIADINA CON
AFETTATO + CAFFE'

31 - 12
ORE 6,40 CAFFE' MACCHIATO
ORE 9 CAFFE' MACCHIATO
ORE 13 PASTA POCA
ORE 14.30 CAFFE' MACCHIATO
ORE 18. PASTA
ORE 23 PIZZA + CAFFE' MACCHIATO

1 - 1 - 2014
ORE 10 CAFFE' MACCHIATO
ORE 13. PASTA + SECONDO + CONTORNO +
DOLCE + CAFFE' MAC.
ORE 19,30 ~~SECO~~ CARNE

Figure 3. Example of a diary. The patient kept the diary for a long time, but with little or no information about her symptoms, and with a repetitive list of the same foods [milky coffee with milk (caffè macchiato), piadina, pasta, vegetable soup (minestrone), barley soup (zuppa d'orzo)]

reduce her symptoms; but it perhaps enabled her to talk about herself, to feel listened to, and despite resistance, to increase her assertiveness and thus acquire a less marginal role within her family.

In the case of another patient, who besides gastrointestinal symptoms presented marked obesity, long-period compilation of the diary made it possible to identify and discuss the woman's binge eating, and thus explain to her the mechanisms that induced the binging. The patient took note. Initially, she was unable to change her behaviour, but constancy and increased awareness enabled her to understand that she did not need food to solve her existential problems with the members of her family and with her colleagues at work. This induced her to listen, to recognize true hunger, to eat at mealtimes, to make more informed choices, and to stop binge eating. Repetition of the diary and examinations thus created more space for intervention. The woman was certainly motivated, aware of the goals to be pursued, and the time that the task would take. In this case the diary, and in particular its repetition, was the means that enabled the patient, the doctor, and the dietician to create opportunities for discussion, evaluation, and management of the clinical problem.

When the symptoms were not attributable to a specific food, and in the presence of a clinical suspicion of food intolerance, the diary was continued in the hope of identifying the pathogenetic cause of the symptoms. In one case, the diary served to identify which component of food was triggering a patient's symptoms. This was done through control of ingredients and product brands: in fact, different brands of the same product triggered the patient's symptoms according to whether or not a particular additive was present. The same reaction could be provoked by products of the same brand, but with different ingredients and therefore presumably with different additives. Repetition of the diary and its high level of detail (dish, composition, brand, and name of the product used) were often valuable diagnostic indicators because they enabled identification of the causal link between symptom and food. A similar pathway was pursued in cases apparently more straightforward from the diagnostic point of view.

All the diaries, regardless of their formal features (complete or incomplete, detailed or concise) were always commented on and discussed with the patient. It was thus possible to hold fruitful meetings even with patients who had kept concise diaries. Emblematic is the case of an 80-year-old woman with constipation who came to our attention because she had been rushed to hospital with intestinal volvulus. After discharge from hospital, for fear of being re-admitted for a disorder which the woman believed to be due to her diet, she reduced her intake of all food. It was thanks to the diary, which the patient compiled regularly, that it was possible to identify, and then correct, the woman's serious dietary shortfall. In fact, the diary revealed that she was not eating an amount of food sufficient for her nutritional requirements; a condition which had not been apparent during the initial interview. Analysis of the discrepancy between the contents of the diary and the woman's verbal account showed that she would avoid eating sufficient quantities of food regardless of caloric content, in the belief that this behaviour would protect her against a further intestinal volvulus. The patient was severely underweight, with depressive traits suggesting the presence of a form of anorexia. Thanks to the relationship created between the dietician and the patient through use of the diary and its discussion, it was possible to address the nutritional issue by activating a nourishment work-up which involved both normal foods and food supplements. Finally, in the case of a patient with chronic diarrhoea, the diary helped understand the patient's attitudes to food choices; choices often discouraged by the doctor or dietician in the presence of such symptoms, but instead regarded by the patient as essential for her mental health. In fact, in order to continue eating food which the patient had been cautioned against but which she strongly desired, she took medication to control the symptoms, or she denied the obvious relationship between the onset of her symptoms and the type of food that she consumed, thereby making her digestive pathology chronic.

Conclusions

Although our experience concerns a single outpatient gastroenterological unit, it confirms the usefulness of the food and symptoms diary in building and maintaining the patient-doctor relationship, particularly in the case of patients with functional gastrointestinal disorders. Use of the diary makes patients feel more cared for and understood, with their consequent perception of greater interest in their problems and needs. Joint analysis of the compilation and content of the diaries enabled better identification of the diagnostic-therapeutic work-up to be pursued with the patient. The closer attention paid to the compilation and completeness of the diary was presumably also due to greater awareness among the health professionals of the diagnostic tool, and consequently also among the patients. This made it possible to activate a more personalized work-up based on more intense dialogue intended to increase the patient's motivation to adhere to the therapy proposed. In some cases, this greater awareness also enabled the doctor to alter the initial diagnosis, which was probably not entirely accurate, in light of new elements, and thus better identify and implement the therapeutic strategy. A further important aspect of this experience concerns the discrepancy observed in some cases between the contents of the diary – which often proved *a posteriori* even more informative about the patient's real condition – and those of the oral interview, which conversely sometimes proved incomplete or even misleading, probably due to reticence on the part of the patient. Analysis of this phenomenon suggests that the patient's development of a real relationship with writing and self-analysis of his or her behaviour and feelings may reveal aspects that instead may be concealed in the verbal discussion between the patient and the health professional. Hence, careful, comparative and joint evaluation of the diary, the clinical examination and the food investigation reports are the cornerstones of the relationship between the patient and the health professional.

Acknowledgements

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Chapter Seven

Negotiating knowledge about illness through television

Valentina Cappi

Ever-present on television schedules, the medical genre has become one of the main arenas of television dramas, a locus of the (re)construction and dissemination of imagery once confined to professionals. However, few scholars have investigated the negotiation between media representations and everyday experiences of health-care contexts. Drawing on field research based on interviews and questionnaires carried out with television viewers and health practitioners in central and northern Italy, this study highlights the ways in which individuals internalize and use in their life-worlds what is shown to them on television screens.

The intention is to determine the extent to which medical dramas contribute to redefining the knowledge, expectations, and practices of viewers/patients in regard to health issues and their role in the doctor-patient relationship. The research results will be evaluated in light of an equivalent study between English and French viewers, demonstrating imagery about medicine which is increasingly transnational, and modes of narrating illness which are increasingly less culturally specific.

Anthropology as an academic discipline has begun to deal with the media system only very recently. It was in fact 1993 when Deborah Spitulnik published an article in the *Annual Review of Anthropology* which began with the disclaimer "There is as yet no «anthropology of mass media" and went on to argue that "anthropologists have managed to neglect the centrality of the media in twentieth century life."[1] On exploring more classic and legitimate areas of inquiry, anthropology has focused more on indigenous media, and the reception of Western products in non-Western countries, than on the mediations taking place in front of televisions in Western homes. Specifically as regards the reception[2] of medical drama television programmes, research seems to have dwelled on other matters. This is confirmed, for example, by the fact that, in 1991, Horace M. Newcomb wrote: "In dealing with television drama, it is incumbent on us to have some theory of how drama, particularly popular entertainment, works in culture, of drama's role historically and in the new mass-mediated context, and the way in which audiences attended to it. ... Television drama may be a «product», but it is a product with special cultural uses."[3]

Speaking on behalf of cultural studies is Deborah Lupton, who argues thus: on the one hand, "the linguistic and visual representations of medicine, illness, disease and the body in elite and popular culture and medical-scientific texts are influential in the construction of both lay and medical knowledge and experiences of this phenomena";[4] on the other, "Because most social scientists have tended not to view medicine as a product or a part of culture, but as an objective body of scientific knowledge external to culture (where 'science' is seen as the antithesis of 'culture'), the cultural studies approach has rarely been adopted to analyse biomedicine or public health institutions and practices. Yet people construct their understandings of the world, including their beliefs about medicine and disease, from their interaction with cultural products as well as personal experience and discussions with others."[5]

There seems to be consensus that media representations of medicine extend beyond the strictly media arena to intersect with, and negotiate on, specific aspects of the audience's lives – among them the doctor-patient relationship. Today, the above-quoted statements may seem self-evident. Yet on analysing the current state of the art, one fact seems clear: empirical research in this area is still very deficient. As regards television hospital dramas, research has focused much more closely on their production or content than on their reception.

It was within research on cultivation in the early 1980s that the first studies[6] were conducted on the effects of the media in the health sector; and they were followed by other studies that carried them forward with criticisms and adjustments.[7]

Nonetheless, in the early 1990s Atkin and Arkin declared that "With few exceptions, very little research had been conducted to assess the impact of health-related content on the public."[8] Incredibly, even in 2004, the introduction to the book *Cultural Sutures: Medicine and Media* stated: "Fictional depictions of doctors and medical procedures in the media clearly have an impact on both the delivery of health care and patient expectations of their physicians. … Yet even with this blizzard of medical information from every imaginable media, few scholars focus on the mediations that occur within that process."[9]

The empirical studies carried out to date in this area can be counted on the fingers of one hand: *Casualty: Reception Study of a Medical Drama* (2000) and *Urgences et ses spectateurs: la médecine dans le salon* (2007) by Solange Davin; and, though of another kind, *Playing Doctor: Television, Storytelling, and Medical Power* (1989) by Joseph Turow and *La confusion des conditions. Une enquête sur la série televisée Urgence* (1999) by Sabine Chalvon-Demersay.[10] This last study analysed the *ER* series by surveying the opinions on it expressed by viewers with different personal, social, and professional backgrounds. As Chalvon-Demersay pointed out, her analysis was not a study of reception, but only a prelude to one. Turow's study concentrated more on investigating the reverse or preliminary process, i.e. it sought "to explore the way powerful forces within an American institution try to guide TV's fictional images of their institution. The institution in this case is medicine. The focus is on the prime-time doctor show."[11] Turow did not abandon the field, and some years later, in 1996, in an article published by *The Lancet*, he formulated a number of hypotheses – which remain such – on the reception of medical dramas. He reiterated that: "There has been no research on what messages viewers with different backgrounds draw from such programmes when the news and personal experiences present them with a fundamentally different reality."[12] Solange Davin's studies on the reception of *ER* and *Casualty* by the French and English public are the only instances of field research on the topic today available.

A simple but persuasive hypothesis as to why so few scholars have attempted such research has to do with the methodological difficulties involved. Qualitative studies on reception are always highly probabilistic, extremely complex, and never fully verifiable. Especially when the data are collected by means of interviews, their analysis is necessarily restricted to the few respondents concerned. As Grindstaff and Turow aptly put it, "the contours of reception continue to shift as more studies are carried out and more types and levels of influence are considered."[13] Moreover, television reception is a more fluid, geographically dispersed, and privatized phenomenon: "Not only is it awkward to enter people's homes and watch them watch television, but television use cannot easily be separated from the rest of everyday life."[14]

Popular culture as an arena for the negotiation of knowledge about illness

It was a fortuitous observation which first prompted the idea of investigating how, in the everyday lives of television viewers, a particular genre of entertainment – namely television medical dramas – became part of negotiations on the concepts of health and sickness by acting on lay explanatory models. By about 2007, it had become impossible not to notice that diverse individuals described their illnesses using highly specific medical and scientific language. Where had they learned that language, that way of acting and describing? Given that those people were not doctors or medical students, did not belong to families involved in the healthcare professions, and were not particularly concerned to inform themselves about health issues, the most obvious explanation was that they all were – or had been – keen viewers of medical dramas. The relationship between the popularity of certain television series and their capacity to penetrate not only the imagery but also the everyday lives of their viewers was well described by Stuart Hall when asked about the popularity of the *Dallas* series. He commented: "At a certain moment the programme achieved a kind of popularity other than merely in terms of numbers of viewers. It had repercussions on the whole culture, the involvement of the viewers became of a different order. At a certain moment you could no longer avoid talking about the popularity of *Dallas* when people started using categories from it to help interpret their experiences. This is a secondary type of popularity."[15]

The notion of popularity is a bridge-concept because of its resonance in both media and cultural studies and medical anthropology. Well known is the far-reaching debate that cultural studies as a discipline has conducted on the concepts of 'popular' and 'popular culture'; perhaps less well known is the division into arenas proposed by Arthur Kleinman in regard to every healthcare system understood as a social and cultural system. According to the American anthropologist, most healthcare systems contain three social arenas within which sickness is experienced and reacted to: 'popular', 'professional', and 'folk.' "These arenas contain and help construct distinct forms of social reality. That is, they organize particular subsystems of socially legitimated beliefs, expectations, roles, relationships, transaction settings and the like."[16]

Whilst the folk arena refers to non-professional specialists, and the professional one to professional scientific medicine, the popular arena principally comprises the familial context of illness and its treatment, although it also includes the social network and community activities. Kleinman estimated that 70-90% of illnesses are managed exclusively in this arena.

In recent decades, television-mediated representations of health and sickness have vigorously penetrated the popular arena. If one considers that it is within this sphere that decisions are taken about whom to consult, whether to follow the treatment, and if it is efficacious, one may well argue that also use of the Internet belongs – and today to a greater extent than television – in this sector (and perhaps also in the folk arena). In short, the popular arena takes the form of a social space in which television and the Internet are acquiring ever-greater authoritativeness in regard to health issues. They sometimes erode the decision-making space always previously granted to the strictly familial context, and they disseminate a single language – that of biomedicine – among different countries and different contexts of care. In theory, none of the three arenas remains unaffected by the pervasiveness of the media. Even the professional arena – in reaction, or in some cases because it is directly involved – reorganizes roles, relations and negotiations in response to a social and cultural context that has changed under the influence of the media. The sociologists Gabe and Bury have rightly included the media among the challenges that face contemporary medicine. They argue that the media act as carriers and amplifiers of a more challenging position in regard to medicine, "both in terms of the latter's knowledge base and of its professional practice."[17] On analysing three different television programmes, Gabe and Bury conclude that media coverage of health and medicine is no longer so strongly affected by medical dominance as claimed by Anne Karpf when she declared that "the box is doctored."[18] Bury and Gabe argue on the contrary that "a more critical view of medical knowledge and treatments, the rise of managerialism and the concomitant divisions emerging within medicine itself cut across the exercise of medical dominance."[19] They add that "there has been a general shift in power and social influence from professional groups, including medicine, towards the media."[20]

The conclusions drawn by the two British scholars can be endorsed with certain qualifications. On the one hand, it is not wrong to maintain that the authority of healthcare professionals diminishes in proportion to the more or less deliberate derogatory campaigns waged against them by the media. On the other hand, it is not so much the messages transmitted by television (still somewhat 'doctored') that are challenging as the uses made of them by viewers.

At the beginning of 2014, when the interviews on which this study is based were conducted with doctors, several interviewees – expressing indignation as well as a certain alarm – drew attention to the constant broadcasting on the main Italian television networks of a commercial urging victims of alleged medical malpractice to sue the doctors. The commercial invited them to contact *Obiettivo riscarcimento* ('Objective compensation'), the telling name of the team of lawyers and medical examiners at the 'counter-insurance' company in question. Similar opinions were expressed in 2008 after the release of *Crimini bianchi*, an Italian television series broadcast on Canale 5 and centred on stories of medical malpractice: “Given the power of television” warned Maurizio Maggiorotti, the president of AMAMI, an association of doctors unjustly accused of malpractice, “the Italian public will be further conditioned by this fiction series, which will besmirch the entire profession, causing an upsurge of lawsuits against doctors: a flourishing business for lawyers and shysters.”[21] Whence derived Maggiorotti’s invitation to professional bodies to lobby the telecommunications authority to halt the broadcast. The series sparked a series of protests reported in the press and on television. Luigi Frati, dean of the Faculty of Medicine at the University of Rome and vice-rector of that university, declared that *Crimini bianchi* “is inappropriate and misleading, as well as copied from an American series. It does not do justice to the many lives saved, the acts of self-denial and sacrifice that all healthcare personnel constantly perform, far beyond what is required by their contracts.”[22] Seemingly more bipartisan was Lorenzo Sommella, medical director of the San Filippo Neri hospital of Rome. He urged that attention be paid to the messages transmitted to viewers because “the criminalization, and the glamorization, of doctors is profoundly detrimental to their relationships with patients.” Sommella also admitted that “the mood of doctors differs according to the series, and I know for a fact that some of my colleagues see *ER* as an opportunity to update their knowledge, because of its modern and realistic depictions of problems.”[23]

One can thus understand the concerns raised by television medical dramas, considering the power that they appear to exercise through their popularity. “The influence of *ER*,” write Gisotti and Savini, “was such that this TV series was credited with the reform of the emergency departments of Italian hospitals according to the organizational model of *ER*, such as the introduction of codes of different colours assigned to patients on admission, or also coloured floor stripes marking the various pathways internal to healthcare facilities.”[24] It is not possible to verify these claims, but it is certain that the dissemination of media fragments, or even of a habitus, inspired by television medical dramas is growing apace. One of the many examples is the habit of doctors to drape their stethoscopes around their necks – the typical gesture of Doctor Carter in *ER* – rather than put them in their coat pockets, as more than one doctor among those interviewed said had been the norm before broadcasting began of Michael Crichton’s series. Moreover, the high-adrenaline depiction of dramatic situations in medical dramas seem to attract some healthcare practitioners, or trainees, to emergency medicine, although they forget that emergencies in casualty wards are usually much less adrenaline-charged. Caterina, a 51 year-old nurse, said:

> I notice that most of my colleagues want to work in casualty and in all the departments which handle emergencies. I don't think it's a coincidence. Almost all the hospital dramas are set in accident and emergency departments, and there is widespread ignorance about paramedics, who are an entirely American category, certainly not an Italian one.

A 'victim' of the same inflated and glamorous representation of emergency was Ilaria, a 25-year-old student, who recalled:

> My dream of becoming a doctor ... was born with *ER*. But then I didn't want to be a general practitioner, I wanted to be a doctor in an emergency ward, where you see people with their eyeballs hanging out ... I wanted to do that because it seemed like a job where you never get bored, there's always tension ... I saw it as something positive.

Other accounts were decidedly more concerned to dispel the sensationalism of television medical series. Among them, the testimonies of some French doctors interviewed by Sabine Chalvon-Demersay were efficacious in their brevity: "I've spent whole nights on duty without being disturbed,"[25] said a doctor commenting on the excessive number of critically ill patients who throng the emergency rooms in medical dramas. And again: "Increasingly, emergency is not what we consider to be urgent, but what patients consider to be urgent," commented one of his colleagues.[26]

Italian television and medicine

In the introduction to his book *Cultural Sutures: Medicine and Media* (2004), Lester D. Friedman wrote: "Medicine, it seems, has replaced baseball as our national pastime."[27] These words were obviously written by an American commentator. Baseball, in fact, has never been the main pastime of Italians. Yet Friedman used this remark to emphasise that, thanks to new and old media, medical events saturate our individual and communal lives. To demonstrate that this observation applies to both the United States and Italy, suffice it to cite some specific data.

Only three weeks after the launch of television broadcasting in Italy by the RAI – Radio Televisione Italiana (then called, for a few months, RAI – Radio Audizioni Italiane) on 26 January, 1954, the national channel aired the first episode of a popular science programme: *Conversazioni scientifiche*. The topics covered ranged from diet to twins, from psychosomatic medicine to sleep. A few months later, the same channel broadcast the first Italian television serial: *Il dottor Antonio*, a four-part adaptation of the novel of the same name by Giovanni Ruffini, which recounted the adventures of a doctor during the Risorgimento period. Only three years earlier, in 1951, the first television series which can be termed a medical drama – *City Hospital* – had begun on the American ABC network.

Hence the world of medicine made its debut on the small screen almost simultaneously with the advent of television in both Italy and the United States. And from the mid-1950s onwards it was offered to television audiences in a wide variety of forms and in regard to diverse topics. Some 480 health-related programmes were broadcast by the Italian public television service between 1954 and 2005.[28] Among those many programmes – some so long-lived that they went into twenty editions – mention must at least be made of those that marked significant stages in the history of Italian television and televised medicine: *Sapere* (1967-1976, Programma Nazionale); *Check up* (1977-2002, Rete 1/ Rai 1), *Medicina Trentatrè* (1985-present, Rai 2), *Elisir* (1996-present, Rai 3). The figures just quoted refer only to popular science programmes and reportage: they do not take account of all the other products offered to Italian viewers in the form of television fiction, docu-fiction, reality shows, or other entertainment genres. The large amount of popular science programmes produced and broadcast by the RAI, which operated as a monopoly until the mid-1970s, is primarily explained by the didactic intent typical of *Paleotelevisione,*[29] i.e. Italian public service television during the first twenty years of its history, when it pursued a threefold mission to 'inform, educate and entertain'. The advent of a competitive market, which was fully accomplished between 1980 and 1984, soon led to a renewal of languages, genres and formats: "from mostly sporadic entertainment used to mark out everyday routine, … TV consumption became a flow organized according to the logic of seriality."[30]

The organization of schedules underwent radical change with an explosion of the fiction genre: the private broadcasters, especially, ransacked the archives of the American networks "in order to fill their daily schedules at low cost with hundreds of hours of American telefilms and soap operas and South American telenovelas."[31]

In this context, Fininvest/Mediaset – the RAI's main competitor which began broadcasting in the late 1970s – gave minor importance to medical programmes at least until the 1990s, when it produced programmes such as *Big Bang – Lo spettacolo della vita* (1985, Canale 5), *Medicine a confronto* (1994, Rete 4), *Vivere bene* (1998, Canale 5), *Medici – Storie di medici e pazienti* (2000, Rete 4). The medical subject became an even greater staple of networks, formats and schedules with the advent in Italy of satellite and digital television in the 1990s. There were several thematic channels dedicated to health, diseases of the body and mind, and the lives of doctors and patients: among them, *Doctor's Life* on Sky channel 440 in 2011 promised to "enter the doctor's house through the front door."

Schedules began to include (mono)thematic evenings: in January 2007, Mediaset offered a '*serata DOC*' (medical drama evening), i.e. the consecutive prime-time airing on Italia 1 of *House*, *M.D.*, *Grey's Anatomy* and *Nip/Tuck*. The formula worked, and was repeated in the summer with *House*, *M.D.*, *Royal Pains*, and *Miami Medical*. A few years later, in winter of 2012, the third Italian broadcaster, La7, consecutively aired *Grey's Anatomy* and *Saving Hope* in prime time.

In the 2000s, medical programmes reached saturation point in the Italian media system. In 2004, the first docu-soap produced entirely in Italy – *Reparto Maternità*, dedicated to the various phases of motherhood – made its debut on Fox Life (Sky). The format was successful, and in 2010 the same channel began broadcasting the docu-fiction *Trapianti. Destini incrociati*, produced by Magnolia and filmed entirely in the liver and multi-organ transplant centre of Bologna's S. Orsola Hospital. In more recent years, as television output has increasingly shifted from fiction to reality TV, the Real Time channel was launched on Sky Italy in 2005 – and then in unencrypted format in 2010. Owned by Discovery Italia, Real Time became the most watched non-fiction channel on digital terrestrial television after the two main networks, RAI and Mediaset. Since its inception it has broadcast numerous programmes dealing with the body, health and disease: among them, the docu-soap *Diario di un chirurgo*; the medical documentaries *24 ore al pronto soccorso* (*24 Hours in the A&E*) and *24 ore in sala parto*, *Chirurgia XXL*, *Food Hospital*; the reality medical series *Malattie imbarazzanti (Embarrassing Bodies)* and *Malattie misteriose*, *Vita al pronto soccorso*; and many others.

Although the lives of doctors and patients are increasingly depicted on the small screen in the docu-drama format – or that of the medical documentary – they entered the homes of generations of viewers mainly thanks to fiction series, which still constitute the dominant television genre nationally and internationally. In Italy, the scheduling of programmes of this type was certainly due to the need to fill daily programming hours; but it was also because "it soon became evident that these products were able to attract the attention of the general public by virtue of their capacity to reproduce the reality without distorting it. They gave good entertainment, but also material with which the audience could consider, discuss and comment on issues and problems of everyday social life."[32]

The medical drama

After its debut on the small screen, the hospital – together with law courts and police stations – became one of the main arenas of televised serial narrative. In Italy, indeed, hospital fiction programmes and their audiences boomed in the 1990s and the 2000s. They became an immediately recognizable genre – medical drama, sometimes also called 'hospital drama.' Episodes lasting between half an hour and an hour and a half depicted the private and professional stories of doctors in a hospital, a clinic, or an ambulance. Interwoven with their work were the lives of their families and patients, as well as the love stories that unfolded in the hospital's closets. In some cases – for instance *ER* (1994-2009, NBC, 1996-2009, Rai 2) – the hospital was represented as a social microcosm reproducing and sometimes exacerbating the dynamics, rules, and relationships of society at large. In others – for instance *House*, *M.D.* (2004-2012, Fox, 2005-2012, Italia 1 and Canale 5) – it is the more strictly diagnostic dimension that is emphasised, so that the medical genre merges with the police and detective format. In a regime of the 'maximum visibility of bodies'[33] as evinced by the *House, M.D.* series, with macro images of internal tissues and endoscopic incursions into the human body, the disease (the culprit to be tracked down) commits its crime, leaving clues (the symptoms) at the scene (the patient's body). Finally, the hospital arena is frequently depicted through the troubles and challenges of a group of young graduates. In *Grey's Anatomy* (2005-present, ABC; 2005-present, Italia 1) as well as in *Scrubs* (2001-2010, NBC and ABC, from 2003 to 2010, MTV), the plots link the human training necessary to accomplish the professional mission with sentimental training, in the former case verging on the more romantic tones of a soap opera, and in the latter those of a screwball comedy.

Italian output is instead characterized by a slower pace and greater lightheartedness, alternating hospital routine with family or community life. In fact, the main character of the hit series *Un medico in famiglia* (1998-present, Rai 1), an Italian production based on the Spanish television series *Médico de Familia* (Telecinco), is the family of the young Roman doctor Lele Martini. The events narrated in the series, which has now reached its ninth season, revolve more around the Martini household than the hospital where the doctor works. The register assumes the tones of a soap opera. Similarly, *La dottoressa Giò* (1997-1998, Canale 5), a series derived from the television film of the same name broadcast two years previously, followed the work of the gynaecologist Georgia Basile in a Rome public hospital. The focus was once again on the doctor's private life and her possible pregnancy, rather than on representation of a professional environment. Different is the case of *Medicina Generale* (2007-2010, Rai 1 and Rai 3), a Rai Fiction series apparently based entirely on the American *ER*. Filmed in a real hospital in Rome, an entire floor of the disused Forlanini Hospital, the series sought to provide a believable account of everyday routine in the medical division of a large Italian hospital. The plots did not shrink from addressing clinical malpractice, poor organization and administration of the healthcare system, and controversial issues. The protagonist was a woman (a recurrent feature of Italian medical-themed TV fiction), a nurse, around whom revolved the characters and stories of men and women at the hospital and her life. Each episode was inspired by an actual event, and the producers consulted scientific advisors on technical details. The series did not achieve the hoped-for success and only went into a second season amid low ratings and, in the summer of 2008, a vociferous press campaign by Italian doctors protesting against the invasion of television by medical series. The controversy was heightened in the same year by a series on Canale 5 entitled *Crimini bianchi* (2008-2009, Canale 5 and Italia 1) and entirely focused on medical malpractice (mistaken diagnoses, exhausting shifts, poor hospital organization, frauds). Nor did this series gain popularity from being controversial, and it was discontinued after the sixth episode.

A rapid survey of some of the most popular medical dramas on Italian television demonstrates how large and diverse is the array of programmes offered to viewers. Evidence of the pervasiveness of medical dramas on national and international channels emerges from a simple exercise in 'TV zapping.' Including digital satellite schedules, this shows that, at any time of the day in Italy, it is possible (indeed, unavoidable) to find repeats of *House, M.D.* or a new episode of *Un medico in famiglia*. A more accurate estimate is possible from a simple count of the television series classified as medical dramas by Wikipedia. We cannot rely on the absolute accuracy of these data, since Wikipedia includes fiction in different formats (mini-series and long series) within the same category, and it excludes others in which medical content, though not predominant, is still present. Nevertheless, the estimate is revealing: on summing Egyptian, Colombian, Japanese, South Korean (fully 27 series!) output, and of course that of many other countries, including the United States (which, together with Canada, records 88) and Italy (7), one finds that fully 271 medical series were broadcast for at least one season between 1951 and 2014. Moreover, already in 1979, when the majority of the series considered here had yet to be produced, a US study[34] showed that about half of the characters in all the series broadcast daily in the United States were concerned with healthcare issues.

To gain an idea of the popularity of these hospital dramas, consider that *ER* and *House, M.D.* respectively occupy first and second place in the ranking of the most viewed television series imported into Italy over the past twenty years, with more than 6 million viewers per episode. Still to this day, the episode of a USA-made telefilm with the largest audience in the history of Italian television is an instalment of *ER* broadcast on 4 December 1997, with 7 million and 179 thousand viewers.[35] The popularity of these two medical dramas is similar in the United States, given that *ER* had a weekly average of 32 million viewers; and *House, M.D.*, which was distributed in 66 countries in 2008, achieved the record for the most watched television programme in the world.[36] If we then consider the figures relative to Italy, *Pronto Soccorso*, a miniseries broadcast on Rai 1 between 1990 and 1992, directed by Francesco Massaro and with Ferruccio Amendola in the lead role, attracted 8 million viewers during its first series, while *Un medico in famiglia*, broadcast on the same channel, had an audience of more than 7 million. Therefore evident, in quantitative terms, is the diffusion of what in every respect can be termed mass-consumed cultural products.

The popularity of the hospital drama genre, the increasingly close attention paid to health, the variety of health programmes on television, together with heated debate on the effects of these products, raise questions as to the linkage between these programmes and their social circulation – or better, the implications of their use by lay persons and medical professionals.

Analysis of the consumption of fiction products has yielded important insights into the state of negotiation between representations of health and lived experience. Firstly, a general finding should be considered: it is now widely accepted that television is society's primary storyteller.[37] As pointed out by Nancy Signorielli, "Its [television's] world both mirrors and leads society ... It tells most of the stories to most of the people most of the time – and thus it is the wholesale distributors of images, and it forms the mainstream of our popular culture. ... it is through these stories that people learn many different things about the world and its peoples."[38] Within this landscape, it is television series, as a popular art form, that possesses "a unique ability to engage viewers in ways that news and public affairs programs do not", and above all has the capacity to reach audiences "that are not as likely to pay attention to news media."[39]

The presence within television fiction of a set of behaviours, values, and social norms with diverse claims responds to a fundamental need of its real users: "their demand for a verisimilar[40] representation – not true and not false – of reality, a representation with which it is possible to compare one's individual and social experience to discover how it differs."[41]

Among television genres, moreover, the fiction serial is the one that best lends itself to ritualized consumption. It not only exhibits a reciprocal relationship with everyday life because of its content (the narrative structure hinges on the constant recurrence of the same settings and the same characters, each of which has specific features and a past history); it also moulds the viewer into a loyal and competent consumer.

The weekly appointment at a certain time in front of the television marks not only the time of television programming but also everyday 'existential' programming. Finally, further continuity between the world of television and people's experiences is created by the fact that television audiences are increasingly less 'mass' audiences and increasingly more 'diffused' ones. As Abercrombie and Longhurst write, this means that "everyone becomes an audience all the time: being a member of an audience is no longer an exceptional event, not even an everyday event. Rather it is constitutive of everyday life."[42]

In this regard, two aspects of the concept of diffused audiences should be emphasised. The first has been highlighted by Laura Grindstaff and Joseph Turow: "researchers must rethink the notion that television is primarily a domestic medium linked to a particular technology."[43] Today, people receive television programmes not only via cable, satellite or the Internet but can consume them wherever and whenever they wish via smartphones and tablets. Consequently, it is more correct to conceive television consumption as inextricably bound up with a broader media flow which, depending on the point of view, can be called 'video culture' (Turow and Grindstaff, 2006), 'mediascape' (Appadurai, 1996)[44] or 'media ecosystem' (Jenkins, 2001).[45]

The second aspect, relative to the decision to undertake an ethnography on the consumption of medical dramas rather than other medical-themed programmes, concerns practical consideration: the fans of medical dramas can be easily found online by visiting the web-based fan clubs or Facebook pages of the television series.[46]

The study: methodology and participants

Following the methodology of grounded theory and media ethnography, used to construct the data were semi-structured interviews, open-ended and closed-ended questionnaires, and impromptu conversations. Because of difficulties in accessing the field, it was not possible to conduct direct participant observation in a hospital setting.

The aim of first part of the research was to determine if and how certain viewers had negotiated knowledge, identities, and social practices from watching medical dramas. The members of the online fan clubs of the most popular – in terms of audiences – television series broadcast in Italy were considered in order to select participants differing by age, gender, employment status, and frequency of consumption. Other participants were found among people who had put a 'like' on the Facebook page of some of the television series considered (in particular, *House M.D.*, *ER*, *Scrubs*, *Medicina Generale*). The fifty-six participants recruited were sent a questionnaire with open-ended questions which entirely matched the outline of the semi-structured interview conducted with those who had made themselves available for a face-to-face meeting (fifteen). The questions comprised a section on how the respondent watched medical dramas (on what platform, at what time, on his/her own, in a group, etc.). A first set of questions explored a more general interest in health issues and the information media channels used for that purpose; a second set investigated understanding of the language used and the meanings attributed to certain situations depicted in the television series, the purpose being to prompt comparison with personal experience in real healthcare contexts. At the end of this first phase, it was necessary to enlarge the sample of respondents. Not used for the study was a statistical sampling method that related the number of participants to the universe of the population. Adopted instead was the theoretical sampling method typical of grounded theory, whereby sampling "is a function of the analytical process and consists in the progressive extension, as the analysis proceeds, of the number and characteristics of the participants … among subjects and in contexts with precisely those characteristics on which the emerging theory is still weak."[47]

On the assumption that, as a result of the greater exposure to the hospital environment, viewers have gained a 'side stage' perspective (Meyrowitz, 1985)[48] on the work of the doctor, it was decided also to explore how negotiation between viewers and medical dramas may have impacted on the doctor-patient relationship.

A snowball sampling procedure was then used to select the healthcare practitioners (doctors, nurses, hospital public relations staff) to be interviewed. On the basis of contacts already established, the names of further healthcare professionals in central and northern Italy were selected, the only criterion being diversity of age, gender, employment status, and speciality. Thus found were gynaecologists, general practitioners, anaesthetists and resuscitators, psychiatrists, radiologists, oncologists, paediatricians, cardiologists, nurses, public relations managers, and so on. Conducted with these subjects were twenty in-depth interviews, on conclusion of which it was decided to expand the sample further. Following a suggestion by the younger doctors among the interviewees, an open- and closed-ended questionnaire was drawn up and administered to first-year students at the Faculty of Medicine of the University of Bologna to determine whether their images of work, and their motivations to pursue a particular career, had been mediated by watching medical dramas when they were adolescents. Seventy questionnaires were collected.

Practices of mediation between fiction and reality

The first results[49] of the interviews showed that it is entirely possible to attribute to medical dramas a role of informal and secondary socialization[50] into knowledge on disease and healthcare organizations. The knowledge thus acquired complements rather than replaces the knowledge learned in the family and the education system. This conviction is shared by Solange Davin, whose study on French viewers of *ER* reports findings similar to those on the Italian subjects. Not all medical dramas were regarded as equally informative or as reliable sources of information. The interviewees considered *ER* to be the most plausible and accurate. They were able to recognize the differences between the American healthcare system (as represented) and its Italian counterpart. But instead of causing confusion, this had induced the interviewees to reflect on the system of their own country and then on an ideal one. Moreover, most of the respondents proved able to distinguish between generic information obtained from television series and the replication and practical application of such knowledge. Surprisingly, the doctor respondents most frequently mentioned the capacity of *Scrubs* to convey situations bordering on the absurd but entirely similar to those which occur in a real hospital ward. Marianna, a twenty-eight-year-old graduate in cardiology, confided that she had experienced her first day of work at the hospital just as described by the protagonist of the *Scrubs* series:

> *Scrubs* is ... very truthful. They have a set-up better than ours, they're more organized, but *Scrubs* ... makes you see how graduate interns are treated like shit. That's how it is. ... The first day, the first episode of *Scrubs*, he [J.D.] comes in and says, 'Right, now I've got a degree, six years ... and I don't know anything.' Which is the truth. I mean, you don't know how to run a department, but they really put you ... they throw you in at the deep end.

Angelina, a 42-year-old anaesthetist and resuscitator, said that she had personally experienced 'surreal' tragi-comic episodes in the wards of her hospital, and that they had demonstrated the veracity of *Scrubs* to her:

> *Scrubs*, for example, matches my experience. I identify very closely with it. First because unlike the other series it shows everyday reality... I mean, a mental everyday reality. This guy who spends so many hours in the hospital, like we do here ... things that aren't mentioned in the other hospital dramas because they do the super-hero thing. In the real world you dedicate a huge amount of your time to the hospital, which is nearly most of your life. And then your life in the hospital mixes with things that may be amusing. This is an irony that you can only appreciate with colleagues, because if you talk about these things in the real world, people look at you as if to say 'What's funny about that?' So there's this sort of ... surrealism. I recognize it. I see myself in it because that's what it's really like. And then it mixes with your life, your feelings, your screw-ups as well. Because that's the way we are. I watch episodes where I see myself as just like him [J.D.], that is, exactly the same.

Besides being a proposal to be interpreted as an audiovisual text, a television medical drama is also a resource. One of the most frequent uses made of it[51] is the acquisition of a repertoire of expressions to be re-used in everyday conversation.

Alessio, a freelance IT consultant aged 26, had no doubts as to where he had learned a new word in the medical lexicon:

> There's one thing I've learned from the TV series: that the suffix '-tomy' usually indicates the removal of a part of the body. So I imagine that [tracheotomy] means removal of the trachea. I must certainly have seen it in some episode, but I can't say how it's done.

Medical dramas are able to furnish images of reality which confirm, supplement, or correct the cognitive maps of individuals. For example, several French television viewers claimed that they had discovered things that they had never known by watching *ER*: "A cancer can cause a broken leg, which I absolutely didn't know", said one.[52] "I didn't know it was possible to carry out internal cardiac massage", another declared.[53] Davin reports the following remark by a nurse: "Everyone in my family watches it. They're glad to get an idea of what I do at work."[54] Among the Italian viewers, Sofia, a twenty-eight-year-old nursery teacher, maintained that television medical dramas had given her insights into the work of health professionals that otherwise would have been impossible:

> All that stress, the terrible shifts they work ... you couldn't even imagine that a surgeon can work for three consecutive days on end, but it happens. And unless you have a surgeon as a relative, you learn it from these telefilms. Me at least, before I watched them, I didn't even imagine such things.

After Catia, a 49-year-old journalist, had watched an episode of a medical drama which gave a tragic representation of the disease from which she suffered, she found herself doubting whether she had been given full information about her affliction. She commented thus on Facebook:

> When a TV series talks about a disease that you've had for years, ... a series that isn't *House, MD* – which I'd prefer – and someone turns up with your disease, and all of them, even the hospital janitor ..., start shaking their heads like the chorus in a Greek tragedy and there's mournful background music … from the bottom of your heart you obsessively ask yourself: what the hell is it that they know and have kept hidden from me?

By contrast, Raffaella, aged 34, a consultant in the banking sector, had her opinions on ethical-medical issues confirmed:

> Personally, I'm struck when they deal with organ donation, as well as the decision on resuscitation. Though I already agreed in principle, the TV series has made me even more in favour of those choices.

Hospital dramas also furnish schemes with which to explain everyday events, often in light of how the programmes treat 'exemplary cases.'

Ilaria, a 25-year-old student of cultural anthropology, recalled that she had understood what kind of drip solution was being administered to her grandmother just admitted to hospital because she had seen the procedure several times on *ER*:

> It was, I think, at the hospital that my father said "They've rehydrated her" and I immediately saw the drip feed, and I immediately thought that it was a saline solution because I'd heard the expression a thousand times ... I'd mainly watched *ER*. When I was at junior and high school I was addicted to it.

Andrea, a 24-year-old student of psychology, had undergone surgery. He said that he had not been completely bewildered in the operating theatre because he had seen its dynamics in television hospital dramas:

> I had an accident which required surgery to screw a metal plate to my elbow. Because I had bronchitis on the day of the operation, it wasn't possible to give me a general anaesthetic. So I remember every minute of the operation, which I watched wide awake for several hours. I must say that, because I'd seen the dynamics of an operating theatre on television, I was reassured. I knew that the surgeon didn't have time to talk to me. I knew that he was doing his job and that he performed operations every day. I knew that the loud music on the radio that I could hear in the theatre was to keep the whole team alert and active, not to entertain them at greater risk to me. If I hadn't seen certain scenes on television, I'd have been more worried.

The use of medical dramas is considered effective not only for the acquisition of linguistic, cognitive, and spatial/environmental information, but also for the internalization of behaviours appropriate to emergency situations. Ilaria, 23 years old and unemployed, admitted:

> I certainly have very vague knowledge, but when I think about what I know about medicine, I reckon that eighty percent of it derives from the television series that I've watched. Some information about what to do in an emergency (for example, don't pull the knife out of the wound), I've got from watching those series.

The same example was mentioned by Lorenza, a 37-year-old journalist, who forcefully argued that medical dramas "furnish information which isn't generally known even though it's basic: for example, don't move accident victims with back injuries, don't remove knives or other objects embedded in wounds."

Some specifications are in order. Firstly, knowledge does not always influence health behaviour, which may instead be altered for reasons unrelated to health.[55] Secondly, given the data collected, it should be borne in mind that the knowledge acquired from medical dramas is forgotten in emergencies or in cases of chronic or severe illness. In such situations, knowledge of the experience of medical practitioners and almost total reliance on their expertise outweigh any other consideration. Nevertheless, analysis of the interviewees' replies revealed traces of social learning. Some respondents even thematized the matter, doing so from discordant positions. Alessio, a freelance IT consultant aged 26, admitted: “I may know a few more words, but it’s unlikely that I’ll need to use these words in everyday life.” Likewise, a television viewer interviewed by Davin said: “I obtained some information about hip replacement, but I didn’t really learn very much.”[56] Elena, a 20-year-old biology student, disagreed:

> I think that once you’ve learned a specific word for a particular thing, it’s hard not to use it. ... I mean, instead of calling things bruises, I now call them haematomas or petechiae. It’s a bit like when you read a book and come across a new word that you like, and then you put it all your sentences, trying to rephrase them so that you can use that word. It’s rather like a new dress. Because a new word is nice, you learn it and use it.

Like Elena, French interviewees claimed to be “fascinated by medical terms”: “I’m insatiably curious. I never stop putting all kinds of questions to my friends studying medicine.”[57]

Familiarization with the hospital, its codes, and its inhabitants

Just as the relationship between education and changes in health habitus is not a straightforward question of causal effect, so it is difficult to establish a direct link between exposure to and a passion for hospital dramas, on the one hand, and the decision to pursue a medical career on the other.[58] Except in a few cases, interviews were conducted with young doctors who claimed to know for a fact that some of their colleagues had embarked on a medical career because they had been seduced by its glamorous portrayal on television. Yet those respondents did not interpret their own motivation in the same way. The reason may have been that they saw the decision as frivolous and therefore kept quiet about it. Also among French viewers, the testimony reported by Davin is rather indirect: that of a mother who described her daughter’s motivation thus: “My daughter has just started studying medicine partly because of the series, and she’s not the only one!”[59]

But preliminary analysis of the questionnaires administered to the medical students showed that a clear majority of them had gained an idea of the doctor’s work before they enrolled at university by watching television series set in hospitals. Only secondly had they done so through experience of hospital when visiting a sick relative, and thirdly when they themselves had been hospitalized.

Some 91% of respondents believed that the mass media influence the attitudes of patients towards doctors, while only 31% thought that they influenced the attitudes of doctors towards patients. A very different finding emerged when the interviews with doctors who had been practising for several years were considered. These respondents declared, and especially the more elderly ones, that they were fully aware that the defensive attitude which they had been forced to adopt for at least a decade was largely a reaction to the doubts cast on their work by the media and assimilated by viewers/patients. 96% of medical students said that they knew what television hospital series dealt with, and 88% watched them or had done so. The titles most frequently mentioned were *House MD*, *ER*, *Scrubs* and *Grey's Anatomy*. 84% thought that the programmes created false expectations: those most frequently cited were the expectation of immediate and positive results from doctors, which if not forthcoming bred the belief that the doctor was incompetent or inefficient, with the consequent dissatisfaction and suspicion; the hypochondria of persons "who decide that they have an illness because they've seen it on television (perhaps personified by an actor in a medical series) and unnecessarily clog the public health service" the expectation that doctors deal with a maximum of two patients at a time, and that they do so in splendid hospitals.

In the accounts collected, however, the patients were fully aware of the distance between hospitals on television and real ones. They did not feel that they had been deceived, and they knew that "some things are not possible in Italy": "I think the most striking difference is the access to resources", said Chiara, a 25-year-old student: "It often appears normal in the television shows to have rapid access, without problems of bureaucracy or expense, to specialist examinations or diagnostic tests or therapeutic options, which in fact are much less readily available."

Of course, there were also respondents who said that they had not learned very much from medical dramas: they watched them for entertainment or to relax because they were more interested in love stories among the doctors than in the medical issues treated. All of them, however, declared that they had been prompted at least once during the series to find out more about certain diseases on the Internet or in an encyclopedia. This is an example of indirect learning that was confirmed by the French viewers: "it makes me want to learn more. I'd like a doctor to comment on the words and gestures and explain them,"[60] ran one of the many examples of this kind.

The data appear to refute some of the hypotheses put forward by Joseph Turow, among others, concerning the impact of medical dramas on television viewers.[61] First is the contention that these representations of health make it more difficult for the audience to understand the debate on real health care. As we have seen, among the testimonies collected there was a stronger desire to be better informed than to believe that things work as they are depicted on the television screen. Second is the hypothesis that, because viewers do not know much about the political backstage and structure of a healthcare system, they attribute doctors with more responsibility and political power in decisions, although those decisions are in fact taken by other actors. Also this hypothesis falters in the case of these particular interviewees – who, in the Italian study, possessed medium-to-high schooling. The respondents realized this; indeed, they had sometimes been made aware of the complexity of a hospital's organizational and hierarchical structure precisely by a television series. Elisa, twenty-two years old and unemployed, said:

> The roles of the staff and the workings of the departments, which I think are the same as in Italian hospitals, are features that aren't overlooked by these programmes. Always present are the hospital director and the department heads, who clarify their functions well and also do bureaucratic paperwork that I wasn't aware of.

By contrast, entirely demonstrable are some of the comments made by Sabine Chalvon-Demersay and supported by Solange Davin, and which give grounds for drawing some conclusions from a comparative perspective. According to the analysis by Sabine Chalvon-Demersay – which focuses exclusively on *ER* – through the mechanisms of realism, identification and idealization, as well as the unity of place, a medical series is able to reverse the spontaneous perceptions of viewers. It makes the television hospital familiar and fosters a sense of security, whilst the hospitals of ordinary life are perceived as dangerous and hostile. It is precisely this 'sense of security' that emerged, in the Italian research, from an interview with Viviana, a 27-year-old waitress:

> Clearly, the knowledge conveyed is not professional or particular, but it seems to give a sense of security, I don't know how to describe it … creating a sort of light and fragmented expertise.

Francesco, an electrical engineer aged 37, said that watching medical settings and personnel on television "makes the patient feel more at ease in an environment that is not normally part of daily life." Of similar opinion was Diana, a twenty-two-year-old nurse, who said that "if the programmes are very engaging, … they may allay people's fears and their dread of hospitals and healthcare workers." A French respondent went further, in that he saw greater confidence in the hospital environment as potentially empowering:

> If you're experiencing something similar, your behaviour may be affected. For example, you won't be so forcibly subject to the doctor's authority. You say 'I know something about it', and you'll be more sure of yourself.[62]

Similarly, according to Chalvon-Demersay, the hermeticism used by the script does not alienate the audience; instead, it contributes to familiarization with the world depicted by the medical series. The repetition typical of the television serial undoubtedly favours this process of 'accustomization' with a new language so that relative familiarity – at least perceived or presumed – is acquired. "They make otherwise very obscure concepts and terms much more understandable to someone without medical training", said Francesca, a first job-seeker aged twenty-six. "For example, I've found myself at ease when hearing and reading medical reports, and I've frequently been able to ask appropriate questions."

Very similar in this regard were the testimonies of a French teacher and Ilaria, an unemployed Italian respondent aged twenty-three years old. "They helped me understand some aspects of hospital reality, mostly devices, objects, and things that I've often seen on *ER*. I mean, saline solution, blood gas, haemoglobin, stuff like that." The French teacher interviewed by Sabine Chalvon-Demersay said likewise:[63]

> My impression is that you begin to understand something even though the world of medicine is really very abstruse. The few times I've been in hospital, I didn't understand anything, but now I'm beginning to understand. … I feel that I understand much better: they clamp it and input negative O2.

Medical dramas have the principal effect of familiarizing their viewers with an alien world. As evidenced by the interviewees, on the one hand medical dramas dispel fears due to a lack of knowledge about hospitals and the bewilderment caused by finding oneself a patient; on the other, they alleviate the fear that arises when things are difficult to understand. The exclusiveness of medical knowledge is thus relativized to enable its appropriation by viewers/patients.

Conclusions: circular and transnational ways to narrate illness

Inspection of the interview transcripts[64] showed that most of the respondents endeavoured to use 'technical' terminology when describing their illnesses to doctors. In other words, they employed language close to the biomedical categories used to define diseases. They justified this behaviour as a way to speed up the diagnostic process, to help the specialist understand, but above all to acquire authoritativeness in relation to him or her. Whilst the use of specialist jargon by doctors is often criticised as a form of exclusion from the doctor-patient relationship, that same jargon may be appropriated by patients and used for the opposite purpose, i.e. to enter deeper into the relationship by appearing knowledgeable and therefore 'worth listening to.' It is likely that this acquired knowledge is applied in a tactical sense, thus becoming 'the art of the weak.' As Michel de Certeau wrote: "They were other within the very colonization that outwardly assimilated them; ... The strength of their difference lay in procedures of 'consumption'."[65]

It is well known that every explanatory model of illness, i.e. every interpretation of disease constructed through cultural categories, has its own importance structure: it makes some data relevant and leads to the dismissal of others. The accounts of the interviewees, though restricted to particular situations, demonstrated the excessive rigidity of the model whereby the doctor speaks "in a sector-specific language of biological functions and behavior" while patients and families, "even when they incorporate terms from the former, talk about sickness in a culture-wide language of experience,"[66] In the early 1980s, Arthur Kleinman hypothesised that the spread of the biomedical model of disease in popular culture might transform beliefs and expectations regarding health in the popular arena, "so that lay people, especially in the educated middle class, are operating with a more mechanistic and less psychosocial model of clinical reality, and are accordingly more interested in technical information and intervention, and less interested in socially meaningful explanations and psychosocial interventions."[67] This would produce, according to Michael Bury, increasing (though not always correct) use by lay people of information once jealously guarded by professionals in the temple of biomedicine, inevitably reducing the doctor's authority as a source of knowledge and broadening the spectrum of possible clinical narratives (including alternative ones) available to patients.[68] However, Bury's thesis was refuted by the viewers/patients interviewed. It is true that the mass media have increased access to information previously possessed by specialists alone, but this accumulated ‘media capital’ has not opened the way to the proliferation of illness narratives. It has given television viewers a notional handbook and encyclopaedia of medical knowledge that instead has had the effect of reducing the culturally specific codes used to represent certain symptoms to biomedical categories. There has thus come about what Michel De Certeau foresaw: “Television brings into the home a magical encyclopedia that can be consulted without any problems of accessibility.”[69]

In this process, the culture recorded by the mass media not only objectifies expressions and meanings that arise from lived experience; it also seems to construct a symbolic universe which overlaps with that experience and threatens to suffocate it. It is only to a small extent because of medical dramas that a kind of biomedical reductionism is being reproduced and becoming legitimate, not only within the professional arena of medicine but also in the popular and folk one. It remains true, however, that the use of popular medical knowledge learned from fiction products and filtered through television gives even greater authority to the dominant theoretical scheme used to interpret the symptoms of disease. From this we can draw a number of conclusions. The first is that the conflict between the biomedical and lay (popular) models is less radical than it appears; more than an opposition, it is a dialectic of circularity. The second conclusion, as this study demonstrates when matched with those by Solange Davin and Sabine Chalvon-Demersay, is that the audiences questioned on the subject, whether French, Italian or British, gave very similar interpretations and declared that they had acquired similar competences. Davin’s research started from the assumption that British and French television viewers give different interpretations to medical dramas. This hypothesis stemmed from the fact that “in France there are relatively few medical dramas, and those broadcast have aroused very little interest, whilst in the UK they are as numerous as they are popular.”[70] Yet the French anthropologist has to admit that “despite this gap, the search for cross-cultural variations proved fruitless: the informants proposed the same issues, and their comments were similar on both sides of the Channel.”[71] This is an aspect which also Sabine Chalvon-Demersay takes strongly into account when she writes that “establishing a logical and unequivocal link between one type of analysis and a cultural affiliation is a tendency that outweighs all other possible factors of interpretation.”[72] Likewise, the Italian participants in the study just presented came from different geographical and familial backgrounds, and they had different levels of education, different degrees of familiarity with the hospital environment, and different patterns of viewing medical dramas. According to Kleinman, the clinical realities culturally constructed within social arenas differ not only among societies but also among the different sectors or arenas of the same medical system, and often among healthcare actors within the same sector. This is true, just as it is true that there are as many ways to represent disease as there are individuals – and even more so, as many as there are individuals at different stages of life or in different circumstances. But it is also true that, through medical dramas, television is helping to spread preferential modes of describing disease and constructing knowledge about it that traverse national borders and imaginations. This confirms an important aspect of the so-called 'diffused audiences' mentioned at the outset: that they "are both local and global, local in actual performance, global in that imagination – not restricted in space and time – is a crucial resource in the performance."[73]

Hence there comes about through medical dramas a cross-cultural incorporation of biomedical terms into other medical systems and a cross-cultural and transnational reconstruction of thought about illness. What this will produce is certainly of interest for future research.

Notes

1 Debra Spitulnik, 'Anthropology and Mass Media', *Annual Review of Anthropology*, 22 (1993), 294.

2 The term is used in the specific sense given to it by Bruhn Jensen: "Reception is a social act that serves to negotiate the definition of social realty in the context of broad cultural and communicative practices" (Klaus Bruhn Jensen, *Media Audiences. Reception Analysis: Mass Communication as the Social Production of Meaning*, in Klaus Bruhn Jensen, Nicholas W. Jankowski (eds), *A Handbook of Qualitative Methodologies for Mass Communication Research* (London: Routledge, 1991), 137.

3 Horace M. Newcomb, *Media Institution: the Creation of Television Drama*, in Jensen and Jankowsky, 1991, 102.

4 Deborah Lupton, *Medicine as Culture: Illness, Disease and the Body in Western Society* (London: Sage, 1994), 78.

5 *Ibid.*, 19.

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9 Lester D. Friedman (ed), *Cultural Sutures: Medicine and Media* (Durham and London: Duke University Press, 2004), 5–7.

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12 Joseph Turow, 'Television Entertainment and the US Health-Care Debate', *The Lancet*, 347 (4 May 1996), 1240-3.

13 Laura Grindstaff, Joseph Turow, 'Television Sociology in the «New TV Age»', *Annual Review of Sociology*, 32 (2006), 116.

14 *Ibid.*, 117.

15 Ien Ang, M. Simons, 'Interview with Stuart Hall', *Skrien*, 116 (March 1982), 14.

16 Arthur Kleinman, 'Concepts and a Model for the Comparison of Medical Systems as Cultural Systems', *Social Science and Medicine*, 12 (1978), 87.

17 Michael Bury, Jonathan Gabe, *Television and Medicine: Medical Dominance or Trial by Media*, in Jonathan Gabe, David Kelleher, Gareth Williams (eds), *Challenging Medicine* (London: Routledge, 1994), 66.

18 Anne Karpf, *Doctoring the Media* (London: Routledge, 1988), 71.

19 Gabe, Kelleher and Williams, 1994, 81.

20 *Ibid.*, 82.

21 Emilia Costantini, 'Fiction sulla malasanità e i medici si ribellano: non mandatela in onda', *Corriere della Sera*, 23 September 2008, 60.

22 *Ibid.*

23 Cited: Roberta Gisotti, Mariavittoria Savini, *Tv buona dottoressa? La medicina nella televisione italiana dal 1954 ad oggi* (Rome: Rai-Eri, 2010), 80.

24 Gisotti and Savini, 2010, 61.

25 "Il m'est arrivé de faire des nuits de garde entière sans être dérangé" (Chalvon-Demersay, 1999, 256).

26 "L'urgence de plus en plus, ce n'est pas ce que nous considérons comme urgent, mais ce que les patients considèrent comme urgent" (*Ibid.*).

27 Friedman, 2004, 2.

28 The figure includes editions (or seasons or cycles) subsequent to the first programmes considered. Source: Teche Rai – Radio Televisione Italiana, 'Programmi TV per la salute', 1954-2005.

29 The term was coined by Umberto Eco, who used it for the first time in the article *Tv, la trasparenza perduta*, included in *Sette anni di Desiderio* (Milan: Bompiani, 1983), 163-81.

30 Filomena Diodato, *Format e palinsesti*, in Stefano Gensini (ed), *Fare comunicazione: teoria ed esercizi* (Rome: Carocci, 2006), 351-2.

31 Giorgia Iovane, *Come si legge una fiction*, in Gensini, 2006, 389-90.

32 Veronica Innocenti, Guglielmo Pescatore, *Le nuove forme della serialità televisiva. Storia, linguaggio e temi* (Bologna: Archetipolibri, 2008), 31.

33 For a detailed discussion see: Antonio Costa, *Il cinema e le arti visive* (Turin: Einaudi, 2002), 349.

34 Mary B. Cassata, Thomas D. Skill, Samuel Osei Boadu, 'In Sickness and in Health', *Journal of Communication*, 29 (Autumn 1979), 73-80.

35 Source: http://www.telesimo.it (cited: Paolo Braga, *E.R. – Sceneggiatura e personaggi* (Milan: Franco Angeli, 2008).

36 Eurodata TV Worldwide, Agence France Presse, *House is the world's most popular TV show* (12 June 2009).

37 Atkin and Wallack, 1990, 26.

38 Nancy Signorielli, *Television and Health: Images and Impact*, in Atkin and Wallack, 1990, 96.

39 *Ibid.*, 126.

40 See in this regard the useful distinction drawn by Stephen Neale between realism and verisimilitude, which, for reasons of space, cannot be elaborated upon here: Stephen Neale, *Genre* (London: British Film Institute, 1980). It will be understood why the category of verisimilitude is by far the most suitable one with which to analyse fiction.

41 Gianni Losito, *Il potere del pubblico: la fruizione di comunicazione di massa* (Rome: Carocci, 2002), 108.

42 Nicholas Abercrombie, Brian Longhurst, *Audiences: a Sociological Theory of Performance and Imagination* (London: Sage, 1998), 68-9.

43 Grindstaff and Turow, 2006, 119-20.

44 Arjun Appadurai, *Modernity at Large: Cultural Dimensions of Globalization* (Minneapolis: University of Minnesota Press, 1996).

45 Henry Jenkins, 'Convergence? I Diverge.', *MIT Technology Review*, (June 1 2001).

46 As of 29 September 2014, more than 44 million people had put a 'like' on the Facebook page of *House, M.D.* and, according to the statistics page, 17.616 people were talking about it at that moment. Most of them were aged between

18 and 24.

47 Massimiliano Tarozzi, *Che cos'è la grounded theory* (Rome: Carocci, 2008), 14.

48 Joshua Meyrowitz, *No Sense of Place: the Impact of Electronic Media on Social Behaviour* (New York: Oxford University Press, 1985).

49 The research on which this article is based is doctoral research conducted by the writer and still ongoing in regard to analysis of the data gathered during the fieldwork.

50 Meant by this expression is the process by which a society's values, norms, roles, expectations and beliefs are transmitted and internalized through the practices and institutions of the social body. Primary socialization occurs in childhood, when individuals acquire the basic abilities necessary to enter society, usually through the school, the family, religious institutions, etc. Secondary socialization furnishes the knowledge and practices that enable the acquisition of particular skills and the differentiation of social roles. In the sociological literature, the media, together with the peer group, the work environment, and many other agents, pertain to this second phase of the socialization process.

51 For a more complete list of the uses made of media texts see: Francesco Casetti, Federico Di Chio, *Analisi della televisione: strumenti, metodi e pratiche di ricerca* (Milan: Bompiani, 1999), 253-4.

52 "Un cancer peut causer une jambe cassée, je ne savais pas du tout cela" (Davin, 2007, 110).

53 "Je ne savais pas qu'il était possible de faire un massage cardiaque interne" (*Ibid.*, 111).

54 "Dans ma famille tout le monde le regarde. Ils sont ravis d'avoir une idée de ce que je fais au travail!" (*Ibid.*, 110).

55 Davin, 2000, *passim.*

56 "J'ai recueilli des informations sur le remplacement de la hanche mais je n'ai pas vraiment appris grand-chose" (Davin, 2007, 116).

57 "Je suis fascinée par les termes médicaux: j'ai une incroyable curiosité. Je n'arrête pas de poser toutes sortes de questions à mes amis étudiants en médecine" (*Ibid.*, 115).

58 Solange Davin cites two studies stating that "The number of men entering the profession has increased rapidly since the appearance of male nurses in *Casualty* (Hallam 1998). So has the number of law students since *LA Law* (Winckler 2002)." (*Ibid.*, note 22, 121).

59 "Ma fille a juste commencé à étudier la médecine en partie à cause de la série et elle n'est pas la seule!" (*Ibid.*, 116).

60 "Cela me donne envie d'en savoir plus. J'amerais qu'un médecin commente et explique les mots et le gestes" (*Ibid.*, 115).

61 Turow, 1996.

62 “Si nous vivons quelque chose de similaire, cela peut conditionner notre comportement. Par exemple vous ne serez pas forcément aussi soumise à l’autorité du médecin. Vous allez dire ‘je suis là’ et être plus sure de vous” (Davin, 2007, 111).

63 “J’ai l’impression que justement on commence à comprendre quelque chose alors que le monde de la médecine est très très hermétique et que les rares fois où je suis allée à l’hosto, j’y pigeais rien et là, j’ai commencé a comprendre. […] J’ai l’impression que je comprends beaucoup mieux: on le clampe, on lui met de l’O2 négatif”. (Chalvon-Demersay, 1999, 249).

64 In the absence of participant observation, I am aware that the results may not faithfully represent the actual behaviours of the interviewees. Nevertheless, as suggested on several occasions by David Morley, it is a social fact of considerable interest that those collected were the particular accounts that the respondents wanted to give of their behaviour.

65 Michel de Certeau, *The Practice of Everyday Life* (Berkeley: University of California Press, 1988), xiii.

66 Kleinman, 1978, 88.

67 *Ibid.*

68 Michael Bury, cited by Guido Giarelli, *La svolta narrativa: l’incontro clinico come negoziazione di significati*, in Byron J. Good, Guido Giarelli, Mary J. Del Vecchio Good, et al. (eds), *Storie di cura: medicina narrativa e medicina delle esperienze* (Milan: Franco Angeli, 2005), 41.

69 Michel De Certeau, *The Capture of Speech and Other Political Writings* (Minneapolis: University of Minnesota Press, 1997), 122.

70 “en France il y a relativement peu de medical dramas et que ceux qui ont été diffuses ont suscita un intérêt assez modeste alors qu’en Grande-Bretagne ils sont aussi abondants que populaires” (Davin, 2007, 7).

71 “malgré ces écarts, la recherche de variations interculturelles s’avéra vaine: les informateurs abordent les mêmes thèmes et leurs commentaires se font écho des deux coté da la Manche” (*Ibid.*).

72 “établir un lien logique et univoque entre un type d’analyse et une appartenance culturelle est une attitude qui écrase tous les autres facteurs possibles d’interprétation” (Chalvon-Demersay, 1999, 240).

73 Abercrombie and Longhurst, 1998, 76.

Chapter Eight

Hospices and end-of-life care: institutional models and historical-anthropological aspects

Giuliana Gemelli

The premise of this chapter is that the work of doctors and healthcare personnel – with particular regard to end-of-life care – requires the ceaseless accumulation of cultural, anthropological, social, and spiritual knowledge. This kind of knowledge extends far beyond care protocols to encompass caring for the person as a whole. It results from a close encounter with 'total pain' where the body and the mind are inextricably bound up with each other.

The concept of 'total pain,' which translates into the practice of caring for the person as an indissoluble whole of mind and body, of psycho-physical and anthropological identity, raises an issue that has characterized the evolution of the doctor-patient relationship over time.[1] This relationship has undergone major changes since antiquity and assumed a strong characterization during the last century. In the second half of the twentieth century, 'new' institutions – hospices – were created to care for the terminally ill, and they became places in which the concept of 'total pain' was transformed into a practice with enduring cultural and anthropological depth. In fact, this approach has deep historical roots which concern, in diverse religious and philosophical traditions, a compassionate and empathetic attitude towards persons suffering pain, and which reach back to the most ancient civilizations.[2] But the hospices of the modern age cannot be likened to those of the past, which had a broader conception of end-of-life care and treated individuals on the margins of society, the sick, but also the poor and needy, pilgrims and migrants.

In both cases, however, in the distant past as well as in the contemporary age it is necessary to consider the anthropological dimension on a global scale. Forms of civilization different in time and space have developed caregiving in accordance with religious traditions. Even in the more recent experience these aspects are of great importance in regard to groups of people who, in diverse geographical and anthropological contexts, are the recipients of care: for example, with a prevalence of cancer patients in the West, and of people suffering from endemic diseases, such as HIV, in non-Western countries, especially African and Asian. Moreover, there is a different tradition in regard to caregivers. In Western countries, these are mostly practitioners with specific tertiary-level vocational training. By contrast, in non-Western countries they are mostly people close to the patient because of kinship, neighbourly ties, ethnicity, or religious persuasion, who are instructed in caregiving in compliance with anthropological and religious traditions which envisage a strong presence of the family close to the patient and less reliance on hospitalization. Analysed in what follows are the different patterns of caregiving in different historical-anthropological and geographical settings. The analysis begins with brief examination of caregiving compared with care. It concentrates on the genealogy of the modern forms of the hospice and leaves in the background – but does not forget – the older traditions that, in fact, though with different connotations, did not make this distinction.

A first necessary consideration with reference to the Western world is that reflexivity, awareness, and empathy are essential components of caregiving and that the latter cannot be developed solely by 'training strategies' based on 'humanistic' principles and addressed – in extemporary or systematic manner – to medical and nursing staff in order to enrich their 'culture.' Rather, it must arise from a constant interaction between the concrete work of caregivers and the issues that arise from the doctor-patient relation. The main humanistic components of caregiving to terminally ill patients are listening and dialogue. These relationships require a large amount of understanding, not only of the patient's person but also of the anthropological, cultural, and religious aspects of his or her life-course. The multiculturalism now predominant in Western societies has profound implications for the doctor-patient relation, and more generally for the activities of the personnel of healthcare institutions most directly concerned with crucial phases of human life. It is a matter of historical fact that, over the centuries, the patient-doctor relationship has undergone profound changes. It has been marked by evolutions and involutions. The 'conscious' origins of the doctor-patient relationship date back to Hippocrates. Reductionism consolidated, in almost paradigmatic form, during the nineteenth and twentieth centuries with the exponential growth of specialization and the predominance of technology in medical care. The patient took the place of the person, with a limitation of the Hippocratic principles that can be summarized as follows: medicine must treat the patient as a whole and not merely seek to mitigate or eliminate individual pathologies; the doctor's duty is not only to support the patient during the course of the illness and alleviate his/her suffering, but also to safeguard him or her against injustice. The doctor must therefore consider the patient in his or her 'complexity' as part of a whole which does not consist solely in the illness.

These principles have been largely disregarded in medical practice. Indeed, they have been stifled by the increasing formalization that privileges scientific protocols, statistical corollaries, and randomization in therapeutic processes, doing so in accordance with the paradigm whereby specialization is the main criterion for legitimation of the doctor's professionalism. Doctor-patient relations, which over the centuries have also seen the growth of the paradigm of disciplines, have undergone a formalization which has generated various 'models': the paternalistic one – in which there is the risk of the doctor assuming an authoritarian role; the contractualist one, which exacerbates the doctor's defensive attitude; and the model which prioritises the patient's autonomy but risks leaving him or her defenceless against the impact of the disease. All these 'models' assert disparity or asymmetry in the doctor-patient relationship, and they hamper the emergence of a person-centred therapeutic alliance. This alliance presupposes a focus on the doctor's role and on dialogue as a decision-making process which is necessarily shared, reflexive, and consequently responsible with respect to subjective expectations, evidence on the progress of the disease, and the therapy's predictions and outcomes. This reflexive and responsible relationality has two interrelated components: the patient's life, which concerns not just survival but life-quality; and the doctor's freedom, which is not absolute, but relative to the patient's life-quality. Dignity is a value intrinsic to human beings; it pertains to them by nature and does not depend on circumstances; nor is it granted or conceded. It is an intrinsic value that generates concern for others and the desire to care for them. Caregiving is something much richer and more complex than care in itself, and it varies from person to person. It cannot be codified in rules and protocols; it requires profound, intuitive and introspective knowledge based less on observation and the recording of clinical data than on listening and maeutics: that is, the ability to bring out latent aspirations, expectations, needs – what words do not say but can translate, in the therapeutic alliance, into a narrative without schematics: fluid, reflexive, personal and above all dialogic.[3]

Awareness of the crucial and 'critical' role of the multicultural dimension, in both synchronic terms – the importance of cultural diversity – and diachronic ones – the stratification of different anthropological aspects – is a key factor in the growth of the vital interweaving of reflexivity, awareness.

and empathy that increasingly characterizes the new paradigm of 'attention to the person.'

The hospice, in its modern institutional forms, is a residential care facility created during the 1960s in Great Britain. It then spread to all the English-speaking countries and is now a reality and an institutional model throughout the world. The definition of a 'hospice' provided by the WHO (World Health Organization) summarizes its essential characteristics: the task of a hospice is to deliver palliative care to people with life-threatening diseases. To understand the correct meaning of this term, one must return to its etymological root: in Latin *palliare* means 'to cover with a *pallium*, a cloak.' In this sense, the expression 'palliative care' denotes all forms of care intended to alleviate the suffering of a dying person by wrapping him or her in a warm cloak (*pallium*), consisting of an all-encompassing care pathway: medical assistance, understanding and comfort. Palliative care relieves pain and suffering. It affirms life and regards dying as part of a normal process that should be neither accelerated nor delayed by unnecessary forms of therapeutic intervention. Care aimed at relieving the pain of terminally-ill patients integrates the psychological, spiritual, and therapeutic dimensions. It furnishes a support system that helps the patient to be active until the end of his/her earthly journey; it adopts a multi-disciplinary approach in order to meet the needs of the patient and his or her loved ones; it improves the quality of life of the care recipient, with possible positive effects on the course of the disease; it can be administered from the early symptoms onwards, also concurrently with chemotherapy and radiotherapy.

The hospice is not, therefore, 'a care facility'; rather it is a vision of the human being, indeed of the whole person, with a body and a soul. This vision, which is expressed through care and moral and spiritual support, therefore corresponds to a universal need, and it is not confined to specific societies and cultures. The hospice is also a locus of encounter between different cultures and anthropological realities, an active framework of dialogue and understanding which over time has superseded the stereotyped view of the relationship between death and life inherited from the past and embodied in the 'disciplining' of medicine. In this regard, the culture and practices of the hospice have been, are, and will be increasingly widespread factors of change in the doctor-patient relation able to fertilize other medical institutions, and above all to change attitudes towards the life-phase that precedes death. This phase is no longer conceived as the isolation of an individual departing permanently from earthly life in solitude and sometimes in despair, but rather as the end of life not just medically assisted but nourished by caring, warmth, and human sharing. It is therefore a phase bound to leave traces, to create legacies; a pathway that does not blank out the memory of a loved one's suffering but is nourished by his or her serenity and dignity, and the love and respect of those who remain.

The hospice in the global context: historical origins and anthropological forms of caring between past and present

The International Observatory on End of Life at the University of Lancaster in the UK believes that more than 33 million individuals could benefit from the availability of a network of institutions whose primary purpose is to care for the terminally ill with palliative care in the broad sense of the term: that is, dedicated to patients with oncological diseases, but not limited to this type of pathology. According to a very conservative estimate taking account of the patient's family members and emotional relationships, such institutions could give comfort to more than 300 million human beings. Thanks to the Observatory, we now have data on the presence of hospices which allow identification of four categories of palliative care development in the world: countries with an established network of operating systems; countries in which the first schemes have begun; countries interested in evaluating their application; and countries in which there is no discussion. Even in countries with an ubiquitous presence of hospices, there is often insufficient knowledge about their purpose and culture. A hospice is not a care system, but a 'matrix' which furnishes medical, psychological and spiritual assistance to the terminally ill and their loved ones. It is not a hospital department, although it can apply the most advanced hospital technologies and skills. Rather, it is a facility whose care philosophy, architectonic structures, and organizational system are synergistically designed to improve the quality of life. Caregiving at a hospice follows an individualized path based on the principle of *attentio* – empathic 'feeling for the other.'

Hospices give considerable importance to privacy. They have private and common spaces where families can be with patients any time of the day and cook their favourite food; where children, and even animals, are allowed to enter; and where the rooms of patients can be personalized. It is common to see hospice residents taking tea in the lounge in front of a fire, perhaps listening to someone playing the piano. In other situations, as I directly observed during a study period in South Africa, the families of patients who are not hospitalized but receive palliative care at a day hospital keep them company during the day. The patients do manual work or engage in recreational activities; they mingle with relatives and family members. The hospice thus becomes a place for socializing, meeting, and sharing, It is also a safe place for those patients who are particularly disadvantaged and do not want to be separated from their loved ones, as usually happens in the case of hospitalization. Moreover, in particularly poor areas exposed to the scourge of HIV, like the district of Soweto in Johannesburg, the hospice is a place where socialization can be a means of prevention which is not enforced but comes about through a process of attentiveness, listening ability, that involves patients and those close to them in the everyday reality of suffering but also of hope. It is also a place to improve the family's economic circumstances, because members trained as caregivers receive financial support. Moreover, hospices are adapted to the lifestyles of the inhabitants of the local area so that they harmonize with the 'landscape' – that is, with the social-anthropological features of the locality. In Soweto, for example, the hospice consists of painted containers, not because of a lack of funds, but because people living in substandard dwellings are more willing to use it; but the standard of care is the same as that of hospices consisting of buildings made of bricks and mortar.

Thanks to the awareness-raising campaigns and pressures for legislative action that arose in many countries around the world in the mid-1970s, and which still today are endowed with boundless dynamism, the hospice is now part of the public healthcare systems of numerous countries, but certainly not all of them . It constitutes a new way to conceive hospitalization because it resumes and adapts to contemporary culture an ancient tradition of sociality, affective and communitarian relations that seemed lost although they had distinguished 'care' in the past.[4]

The first known initiative dates back to the Roman emperor Julian the Apostate, in the fifth century AD, when a matron of the gens Fabia, a follower of Saint Jerome, founded a hostel for wayfarers, the sick, and the dying in Rome. In the Roman world the approach of death was a moment that involved the social group to which the dying person belonged. As shown by the iconography of the time, female figures were constantly present. It is therefore not surprising that the initiative to create the first known hospice in antiquity was taken by a woman: Fabiola, a Roman matron converted to Christianity.

In the Middle Ages these institutions became widespread with the increased inflow of the poor to urban areas. In modern times, it was an Irish nun, Mary Aikenhead, who founded in 1846 the Our Lady's Hospice in Dublin, specifically devoted to care for severely ill and suffering patients. In France, in the same period, Madame Garnier founded the "Women of

Calvary" association and opened houses for the accommodation of the poor and dying in Marseille, Rouen, St. Etienne and Paris (born from these initiatives was the largest modern hospital for terminally ill cancer patients in the world, the Calvary Hospital of New York, founded in 1899). At the end of the nineteenth century, through a subscription sponsored by the Times newspaper, the Hostel of God, a hospital for terminally ill patients, was opened in London. It was followed by the Methodist St. Luke's Hospice in Bayswater and, in 1902, by St. Joseph's Hospice. The moment when the old tradition of the hospice for the sick and indigent, and for pilgrims gave way to the creation of modern hospices centred on the care of terminally ill patients corresponds to the charismatic figure of Dame Cicely Saunders, who in 1967 founded in Sydenham – a suburb of London – the St. Christopher Hospice, the forerunner of the modern hospice.[5] St. Christopher's Hospice was decisive for the development of the discipline known today as palliative medicine, but especially for the introduction of the concept of 'total pain' and the practices to deal with it.[6] The history and the institutional progress of the hospice created by Cicely Saunders are well known. Less known are their origins, which were the dramatic effects of the Second World War, and the Holocaust in particular. In an essay published a few years ago, the historian Paul Weindling showed that the origins of the hospice in the contemporary age were closely bound up with the need to give succour to the survivors of the Nazi concentration camps, most of whom were terminally ill. The concept and practice of 'total pain' stem from these terrible origins.

"Cicely Saunders," Weindling writes, "was a medical social worker in a London hospital. She met David Tasma, who had escaped the Warsaw ghetto. As David spoke of his impending death, she began to comprehend, "…we needed not only better pain control, but better overall care. People needed the space to be themselves. I coined the term 'total pain,' from my understanding that dying people have physical, spiritual, psychological and social pain that must be treated."[7]

If we change continents and consider a highly dramatic situation like the struggle against apartheid in South Africa, we observe that the creation of hospices where doctors and nurses belonging to different ethnic and religious groups cared for patients also belonging to different communities was an integral and dynamic part of the country's democratic growth. It created a 'silent revolution' that generated a movement able efficaciously to flank the anti-apartheid struggle. It is interesting that this movement developed almost simultaneously in countries characterized by poitical and social turmoil like South Africa, and in democratic North America. In 1974, the Connecticut

Hospice began providing home care, and a similar scheme, run by St. Luke's Hospital, was begun in New York. In Canada, at the Royal Victoria Hospital of Montreal, a surgeon, Balford Mount, opened the first in-hospital hospice ward: the Palliative Care Service (which was the first to adopt the term 'palliative care').

Today, palliative care programmes are present in more than fifty countries. In the USA there are more than 3,000 palliative care centres, and 1,600 of them are part of the American public health system, with forms of management that differ according to models of the public/private relationship. In the United States, where it is possible for a patient with a life expectancy of no more than six months to join a palliative care programme, many hospices are run by trusts similar to private foundations: that is, they are connected to the activities of community foundations. In Britain, there are more than 400 hospices of modern type furnishing an integrated system of residential and home-based palliative care. Australia and New Zealand now have extensive networks of home care services and hospices. The United Kingdom and Australia display greater cultural openness to palliative care, given that for many years they have had university chairs in the subject. In Canada approximately 350 hospice programmes have been activated; and initiatives are being developed in Asia, Korea, Japan, Hong Kong, Singapore, and more recently India. In Africa, hospices operate in Zimbabwe, Swaziland, South Africa – with a particularly extensive associative network – and Somalia. In the Middle East, Israel was the first country to create a significant number of hospices, contrary to the countries of the Arab world, which are only just beginning the process – for political reasons but also, and especially, religious ones (rejection of opiates, primacy of the family in caring for the dying person, specific prescriptions on approaching the dying person's body).[8] New and important projects are reported throughout Latin America, from Mexico to Uruguay, Colombia to Argentina. In continental Europe, despite the presence of a widespread network of hospices, only Catalonia has set up a public system of palliative care and a complete training system. Catalonia is an interesting case because it has demonstrated how to design and implement a comprehensive palliative care system and highlighted the possibility of extending this methodology to geriatric and chronically ill patients as well. In the United States, and to a large extent in England, the creation of hospices has been facilitated, as said, by the presence of an extensive system of community foundations. Governed by a board representing the local community, community foundations have often helped activate the schemes vital for full achievement of this institution's aims, which, as said, concern not only medical care in the strict sense (palliative care) but also the creation of support networks furnishing social, emotional, spiritual, and emotional solidarity. Community foundations have fostered synergies between foundations and voluntary organizations by framing the development of hospice care in the context of institutional philanthropy.[9]

Hospices in Italy: some quantitative and qualitative aspects

Vittorio Ventafridda and Giovanni Zaninetta of Domus Salutis of Brescia can be considered among the pioneers of palliative care in Italy. In Bologna, the original idea of creating a residential hospice was conceived and supported by Professor Cesare Maltoni and brought to organizational and institutional fulfilment by the initiative of the female entrepreneur and philanthropist Isabella Seràgnoli. The first Italian residential hospices were created at the end of the 1980s, and for around a decade also Italy has had a network of these institutions. In the majority of cases, hospices have been created on private initiative, possibly with the support of public funds. In 1999, the Italian state undertook with Law 39 to finance the regional administrations that would develop projects on palliative care and in particular hospices. In 2001, the regions submitted to the Ministry of Health a model of intervention divided into four different levels: home care, hospice, day hospital, and outpatient care. Envisaged was the creation of 'Palliative Care Units,' at least one per province, with the task of coordinating the activities of existing facilities.

The amount allocated by Law 39 was around 230 million euros, but only a few regional administrations took action, and many hospice projects have still not been implemented, despite having received the Ministry's approval since 2002 The scarcity of regional funding has had an inevitable impact on the development of facilities, with the result that the greater frequency of home care has in some cases meant fewer places available at hospices, whilst the problem is not to oppose the two services but to integrate them in a manner beneficial for the patient and economically productive for the community. Until recently, compared with the projected number of 180 hospices only around sixty were functioning, mostly in Northern Italy; many of them were not financed by the state, but by funds raised by non-profit organizations. The model dominant in southern Italy is home care; whilst in the north of the country, home care and hospice care form a relatively efficient system, although they are not always perfectly aligned. In recent years, the impetus imparted by the legislation, the proliferation of initiatives by individuals and groups, and increased public awareness have had important roles in accelerating the process, while responsibilization has resulted in careful monitoring – as evidenced by the White Paper on Hospices. Today in Italy the presence of hospices is, however, still markedly asymmetric. There is a large number of them in Lombardy and Emilia-Romagna – also due to the support of private foundations, such as the network created in Bologna by the consortium headed by the Fondazione Isabella Seràgnoli – and relatively few of them in the southern regions. But there are high expectations concerning the growth and spread of hospices, and the public is no longer unaware of the importance of these organizations devoted to care of the person. Currently in progress is legitimation of the concept of 'total pain,' which extends outside hospices and enriches therapeutic aspects beyond the reductionism of care technologies.

In Italy there are two main factors impeding the spread of this philosophy of intervention: economic and cultural. Some opioids are not marketed because pharmaceutical companies do not consider them cost-effective, given the rates with which they would be reimbursed by the state. The second main obstacle is a cultural misbelief on the patient's right not to suffer tied to religious beliefs, and in particular the idea that suffering leads to the Kingdom of Heaven. In addition, the characteristics of many analgesics are not fully known either to specialists or family doctors, who fear the side-effects of opiates, which they believe may shorten the patient's life. Moreover, they have little familiarity with the procedures required for the prescription of these drugs. Specific attention should therefore be paid to an educational model and a training strategy specifically aimed at disseminating information still little known. For these reasons, comparison with international experience is crucial, and so is careful analysis of the programmes and initiatives implemented by the regional administrations, universities, and hospices themselves.

Anthropological and cultural aspects are therefore of key importance for the organizational culture of hospices – particularly in regard to cross-fertilization between disciplines and knowledge resources – in the process of configuring a new concept of care. Every hospice resident is worthy not only of the highest respect for his/her uniqueness interwoven with personal episodes and relationships, but also for the human and collective values of which s/he is a participant and interpreter, for his/her religious faith, and for his/her emotional, cultural, and anthropological approach to suffering and death. Conscious respect for these aspects of the individual's life and anthropological belonging entails the organization of services able to ensure the best care possible, but also the safeguarding of individuality as a holistic resource for society – a notion that is flattened if not ignored, in a purely bio-medical conception of care. From this point of view, the automatic application of models drawn from Western experience to countries in the developing world is not only unrealistic but also unlikely to take adequate account of the changes caused by migration in the societies of the West. An enlightening example of this is Italy's experience in recent years.

The current state of knowledge and the need for comparative studies

The majority of non-Western cultures consider illness with conceptual categories and anthropological approaches very different from those of Western medicine. For persons of different cultures, strict religious observance and the community's support can be decisive in their approach to issues relative to the final phases of life. Any proposal to extend the network of hospices should consider these factors, because cultures – which are responsible for our vision of the world – have very profound impacts, and the representation of disease reflects their implications. Diverse provenances and diverse anthropological and cultural roots may be reflected in different notions of the nature and meaning of illness and death. A project centred on multiculturalism should develop pathways by launching a cross-fertilization process that strengthens the intangible values produced by best practices. Intangible values are bound to become increasingly important because they foster a relational knowledge exchange whose effect is also apparent in the increased tangible benefits of investing in physical and human capital. The enhancement of human resources through improvement of the skills of hospice staff, as well as the role of local communities and institutions – civic associations, foundations, and firms – in the construction of networks and innovative models may transform the hospice of the future into a 'matrix' for the development of forms of socially responsible entrepreneurship in health care oriented to the values of 'sustainable medicine.' The innovation produced within a process of continuous adaptation to changing environmental conditions can be replicated and applied also in other communitarian areas, transforming itself into policy able to generate evolutionary pathways highly likely to be sustainable. For these reasons, civic entrepreneurship should be subject to careful reflection, with the understanding and learning gained therefrom being used to propagate its effects through enhancement of its planning and operational principles. The innovation produced by scientific research may arise from careful and systematic analysis of international discussions on the taxonomy of palliative care, and include reflection operationally oriented not only to cancer and HIV but also to other types of pathology, including the increasing widespread pandemiological effects resulting from the association between different types of severe diseases, such as tuberculosis and HIV.

The International Observatory on End of Life at the University of Lancaster has in recent years developed an important approach to the international reality of hospices. It has provided documented analyses and conducted extensive cross-country surveys. The focus on ethnographic and historical features, as well as data on health and the policies implemented avert the risk of theoretical metonymies and offer an opportunity to create an international research network,

Despite their very different approaches to hospice care, Italy and South Africa are particularly interesting cases in the international panorama.

Reconstruction of the pioneering Italian schemes enables analysis of the current configuration of hospices in Italy. Despite the still small, though growing, number of facilities, the last three years have seen the exponential growth of projects driven by the rapid and intense development of research and training in palliative care (postgraduate and master courses, in-service training, and conferences). With some notable exceptions, these issues – as said – almost exclusively relate to oncology, which is also the main concern of hospices. But there are exceptions also in Italy, where some hospices, particularly in the northern regions, have developed a broader taxonomy which defines as terminal diseases not only tumours but also certain neurological pathologies of particular severity, and HIV. From this point of view, the European exceptions resemble the models prevalent in the English-speaking countries.

In South Africa, hospices and the relative training in palliative care have more complex features, and for epidemiological reasons their focus is centred on HIV. Moreover, whereas in Europe and Italy the adaptation of facilities and care practices to the socio-ethno-cultural and religious context is a matter of relatively little concern, in Africa and other continents it is of paramount importance – to the point that the design of hospice facilities, staff training, and organizational culture are very different. Conversely, in some European countries, and specifically in Italy, scientific institutions and universities, as well as civil society, are more closely involved with the growing participation of foundations in promoting, organizing, and managing hospice facilities, or raising funds for them, through associative networks, targeted programmes, and collaborative projects. However, in Europe, and especially in Italy, there is less incisive reflection on the complex nature of the concept of terminal disease, given that standards are primarily defined on the basis of cancer. Some Italian hospices have not restricted themselves to fund-raising alone; they have also sought to strengthen scientific research and training networks. In most cases, however, it is evident that the multiculturalism factor is under-determined in

Italy. Whilst this is the weak aspect in the Italian context, it is the strong one in South Africa and other countries, where, however, the involvement of universities, scientific institutions, and civil society (foundations in particular) is only at its beginnings – although it is highly promising for the future. Courses in palliative care are mainly delivered within hospices, and vocational training in this field is still at the developmental stage. Another advance of great importance is the spread of concern for aspects of spirituality, which is one of the features of the hospice culture emerging in some areas of Eastern Europe and in India. It is evident that the practical-operational aspect of this study of the contexts and organizational cultures of hospices tends to value, both conceptually and operationally, two heuristics: the principle of 'sustainable medicine,' and the principle of 'cross-fertilization' based on the collaborative interaction among best practices as well as partnerships for cooperation, knowledge-gathering and operational matters. The goal is to train staff who can operate in different countries, and different cultures, to achieve cross-fertilization effects among best practices based on collaboration with experts and researchers at public- and private-sector institutions, as well as on nursing practice and knowledge-gathering aspects with a specific emphasis on human sciences, spirituality, and ethics. Moreover one should stress the role of networking intended to raise awareness of the rich system of community foundations to broaden the horizons of the approach to encompass multiculturalism as an intangible value of a type of organizational intervention in the social-health sector, in Italy as well as in other countries. In this context, also the specific array of skills that characterize hospices is of great value. At hospices, unlike other care institutions, nursing – i.e. the role performed by nurses not only as catalysts of a network of competencies but also as pioneers in the creation of hospices – is a factor that warrants attention and reflection. Cicely Saunders was a nurse. The matrix has been repeated over time and in different places, if not in the same form at least with the same motivations – as in the creation of the first children's hospice, Helen House, which opened in London in the early 1980s after a long period of planning. The founding of Helen House was due to a mother's determination to turn her suffering into a generator of value, sharing and succour, and to the equally strong determination of a nurse to continue that mother's vision, commitment, and legacy to bring the hospice into being.

From the present to the future

The more deeply one becomes aware that life and death are two parallel and inseparable processes, the more one is able to withstand the pain caused by the loss of a loved one. We often meet people to whom profound suffering has given a particular sensitivity that motivates them to help others in similar situations of suffering, and who develop a salvific power which is spiritual in nature and not related to the conventional concept of 'healing.' It is as if these people have become imbued with a hidden and powerful energy which they are able to pass on to others and which evokes the Jungian metaphor of the 'wounded healer.' Jung derived this metaphor from the Greek myth of the wounded doctor who expressed the divine truth of Asklepios that only a wounded physician is able to heal.

Equally common – unfortunately – is the opposite pattern: persons unable to cope with suffering and who seek to exorcise it by developing egoistic or narcissistic behaviour that induces them to shun humanity and utterly isolate themselves. It is with respect to these people that knowledge of the hospice experience may have a therapeutic 'rebirth' value by performing a salvific function.

Another key aspect of the profound philosophy that characterizes this experience is the principle of the 'concentration' of time into the density of a experience lived within an objectively limited temporal space. In her famous essay, *Traum und Tod*, on the dreams of the dying, Marie-Louise von Franz introduced the concept of *enantiodromia* based on the philosophy of Heraclitus. The term *enantiodromia* literally means going in the reverse direction to time at particularly fraught moments or in extreme life-situations, when a dominant phenomenon affects the conscious dimension and brings out – in synchrony – the unconscious dimension. In this particular situation, which is similar to the perception of the end of life, it is the person in the wholeness of his or her identity and history that takes precedence over the 'patient.' Thus the recipient of care and therapy becomes the subject of a caregiving intended to generate the best possible quality of life in the pathway leading to a new dimension of transition that is not withdrawal from life but full experience of it, with respect for affective bonds, social and cultural origins, and identity, through enhancement of an investment that is also economic and has its *raison d'être* in the 'social and moral return' that it yields.

What, therefore, is the future of these complex and holistic institutions endowed with an innovative paradigm that now necessarily extends beyond their boundaries, not only territorially but also in regard other institutional and organizational domains of 'care'?

A predominant position appears to be emerging in the current debate. The purpose of a hospice is not solely to deliver palliative care; nor can the latter be restricted to cancer patients alone. Palliative care is certainly the fundamental therapeutic concern, but it should be interwoven with other forms of caregiving, individualized and holistic, based on the introduction into therapeutic institutions of a new vision that can be termed 'sustainable medicine.' This is based on the *person* and on society's responsibility to provide, on economically and socially responsible criteria, respite from the 'total pain' of persons in the terminal phase of life. The core theme of this paper has been the disruptive role of end-of-life care with respect to the bio-medical paradigm received from the last century. Superseding a narrow, specialized, exclusively biomedical and 'curative' conception of medicine is an endeavour that culturally is certainly not restricted to hospices, for it concerns the entire domain of the suffering person's care and well-being.

Taking this point of view also means adopting a different stance on experiences in other cultural and anthropological contexts in which life and death, and especially the relationship between them, have different symbolic and practical features. It entails the simultaneous enrichment of tangible aspects (organizing hospices in terms of human resources enhancement) and intangible ones (extending the horizons of multiculturalism). Overall, it requires greater incisiveness to be given to the role of hospices as vectors of civic entrepreneurship. Their associative networks should be extended through the assistance not only of the public and private bodies that fund them, but also associations, local communities, and citizens, the purpose being to generate a process of institutional innovation. This process can be imitated and replicated so that it becomes the driver of new policies in which a vision originally restricted to a few individuals becomes an asset for the entire community.

Notes

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2 Giuliana Gemelli, Guido Biasco, Anna Laura Trombetti (eds), *Hospice and Multiculturality* (Bologna: Bononia University Press, 2014).

3 Ezekiel J. Emanuel, Linda L. Emanuel, 'Four Models of the Physician-Patient Relationship', *Journal of the American Medical Association*, 267: 16 (1992), 2221-2226.

4 http://www.hospice-history.org.uk/

5 The bibliography of Cicely Saunders' writings is huge. Some references for further reading are the following: Cicely Saunders, 'Care of the Dying. Control of Pain in Terminal Cancer', *Nursing Times*, October 23 (1959), 1031-32; Cicely Saunders, 'Care of the Dying. Mental Distress in the Dying', *Nursing Times*, October 30 (1959), 1067-69; Cicely Saunders, 'Care of the Dying. The Nursing of Patients Dying of Cancer', *Nursing Times,* November 6 (1959), 1091-92; Cicely Saunders, 'Care of the Dying. When a Patient is Dying', *Nursing Times,* November 19 (1959), 1129-30.

6 David Clark, 'Total Pain: the Work of Cicely Saunders and the Hospice Movement', *American Pain Society Bulletin*, 10: 4 (2000), 13-5.

7 Paul Weindling, 'From Holocaust to Hospice and a New Ethic of Care', *Giving. Thematic Issues in Philanthropy and Social Innovation*, 2 (2007), 159.

8 Omar Bortolazzi, *Palliative Care and Pain Management in Lebanon and The Role of Lebanon's Independent and Non-Governmental Associations: Balsam and Sanad* in Giuliana Gemelli, Guido Biasco, Anna Laura Trombetti (eds), 2014.

9 Marc Nixon, 'Blended Values: The Hospice at Mary Court. A Model for Palliative Care', *Giving. Thematic Issues in Philanthropy and Social Innovation*, 2 (2007), 225-31.

Chapter Nine

Between tradition and innovation: blended values and approaches in a palliative care ward in Saudi Arabia

Omar Bortolazzi

Physical and emotional distress in the Islamic tradition

According to a *ḥādīth*[1], the Prophet Muḥammad said: "I find it strange on the part of a man of faith that he should grieve at his ailment; if he knew what (goodness) is in his illness, he would love to be ill until he meets his Lord."[2] At the same time there is another *ḥādīth* that implies a different reading: "There are some of God's people whom God carefully saves from being killed and from illness; He causes them to live in health and to die in health and bestows upon them the honor of martyrs."[3] The Qur'ān explicitly recognizes that "On no soul does Allah place a burden greater than it can bear; it gets every good that it earns, and it suffers every ill that it earns" (2:286).

In Islamic belief, suffering plays an important role in life. In Muslim societies, sickness and suffering *are* a part of life. Healing is a reflection of the message contained in the Qur'ān: "And We reveal of the Qur'ān that which is a healing and a mercy for believers" (17:82). Emotional and physical suffering caused by illness is regarded as a test of faith in God,[4] and healing – likewise deriving from divine intent – requires an act of faith in God.

Muslim patients do not consider illness to be a punishment from God. They believe that dying is a part of living and an entrance to the next life; a transformation from one life to another, a part of a journey, and a contract and part of their faith in God. The Qur'ān declares, "They (true believers) say: To God we belong and to Him is our return." (2:156). Anything else that can be said about pain and illness Islām interprets as being part of the interaction between humans and God.[5] The general philosophy in Islamic medicine acknowledges that the healer is Allah and that the doctor is the instrument that God uses to heal people. The approach that guides health professionals, wherever they operate, in combatting disease combines medical knowledge with humanitarian principles: humanity, neutrality, impartiality and independence.

In Islām, religion and medical care have similar basic premises concerning the nature of human beings and their responsibilities. Both Islamic religion and medicine consider human beings to be imperfect creations that require elevation to the ideal status envisaged by Islām. Consequently, the 'imperfect human being' must obey the recommendations conveyed to him/her by both his/her religion and the medical professionals.[6] For their part, Muslim healthcare professionals treating end-of-life -patients follow their oath under the watchfulness of Allah, so that their professional lives should express their Islamic commitment not to betray Allah and the Prophet. The Muslim physician is obliged to respect the patient's traditions and habits, and provide all those responsible for the patient with details of the planned treatment.[7]

Against this background, given that religion is important to most Muslim believers and that it certainly permeates everyday practices in a country like Saudi Arabia — one may ask whether it contributes best to the practice of medicine in general, and to end-of-life treatment or palliative care in particular. What are the right forms and means with which to satisfy religious and spiritual needs in times of severe distress for the patient and his/her family?

Religion and faith, as practised in a specific culture, acknowledge both hope and limits, and thereby assist the patient as s/he struggles to find meaning in the experience of suffering and death.[8] The physician who empathically interacts with and understands the patient's cultural background may gain further understanding of his/her needs and distress. In this way, more effective bonds can be formed and which, in turn, will help the physician to guide the patients' choices better.[9]

Suffering is considered to be a part of life, and acceptance of hardship is greatly rewarded in Islām. Islām teaches that pain and suffering delete sins: "O my son! Establish the prayer and enjoin the right and forbid the wrong, and be patient over what befalls you. Indeed, that (is) of the matters requiring determination." (31:17)

At the same time, treatment to reduce pain and suffering is mandated in Islām. Islāmic teaching encourages Muslims to seek treatment when they fall ill.[10] A *ḥādīth* states: "Seek treatments, because Allah did not send down a sickness but has sent down a medication – known to those who know it and not known to others except for death."[11] Pain relief by analgesics, including morphine, to prevent suffering is allowed and recommended, even if it hastens death, because actions are judged by their intention. Muslims believe that pain expunges sins, but pain must be treated because God opposes human suffering.[12] When death approaches and is unavoidable, Islām directs that the patient be allowed to die without heroic measures or supreme efforts.[13] Medications and medical technology should be used to enhance the patient's quality of life during the time left for him/her. The discipline of palliative medicine has embraced the notion and practice of sensitive care in end-of-life situations. The use of multidisciplinary teams in palliative care to help patients and their families through the dying process (as well as to assist in resolving conflicts in management plans at the end of life) has proved extremely valuable.[14]

A holistic approach

Central to Islamic teachings are the connections and reciprocities among knowledge, health, holism, the environment and the oneness of God (the unity of God in all spheres of life, death, and the hereafter). Islām provides a holistic framework that considers the physical, spiritual, psychological, social and environmental needs of an individual.[15] Dying is a four-dimensional activity: it is more than physical, and the physical and social dimensions merge together as do the psychological and spiritual.[16] Islām does not distinguish between religion and spirituality. There is no spirituality without religious thoughts, practice and experience.

> In the Muslim worldview, God gives rights that cannot be separated from duties toward the Creator and fellow human beings. For example, while all healing ultimately comes from God, Muslims have a duty to seek out medical attention when ill and a right to receive proper medical care. Physicians have a proper clear obligation to provide medical care. The reciprocity of rights and duties differs from the Western conception of inherent and inalienable rights.[17]

Palliative care requires a strong interdisciplinary approach. It embraces a number of different frameworks and approaches to meet the needs of the 'whole' person. And if there is a distinctive feature of the doctor/patient relationship in palliative care, it is certainly represented by the fact that palliative care physicians consider the person as a whole. When they speak of the many dimensions of dying, and aim to provide maximum comfort and support, they are engaged in a wide-ranging endeavour. Moreover, the origins of palliative care lie in the areas of religious care and nursing, rather than medicine, and palliative care draws heavily on a broad spectrum of disciplines, knowledge, skills, experience and creative thought.[18]

Palliative care improves the quality of life for patients and families grappling with the problems associated with life-threatening illness. It does so through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems. Palliative care provides relief from symptoms. It neither hastens nor postpones death; it integrates physical, psychosocial and spiritual aspects of care; and it provides a support system to help patients live as actively as possible until death, as well as a support system to help the family to cope with the patient's illness.[19]

Palliative care teams may include nurses, doctors, social workers, volunteers, spiritual/religious counsellors, allied health practitioners, and a multitude of other therapists. Medical science has acquired new understanding of the interplay among the physical, functional, emotional, psychological, social and spiritual aspects of well-being; and more recently it has supported the development of multidisciplinary approaches.[20]

This in no wise contradicts the traditional Islamic teachings. Historically, Islām has advocated a system of pain control, and Muslim culture fully supports contemporary palliative movements. The general consensus of Muslim belief is that the community must sustain the believer until it is obvious that the believer must face God.[21]

When the end of life looms inevitable and is not just an abstract awareness, a host of social and emotional preoccupations overwhelm patients, families, and clinicians alike. It is important for physicians to aid patients and their families proactively before the end of life in order to mitigate the fear, loneliness, and uncertainly that often accompanies the dying process, especially in today's fragmented medical environment.[22]

The spiritual dimension

Cure and *care* involve the spiritual-divine domain. Consequently, both the physician (or caregiver) and the patient operate with blended values of ethical and Islamic expectations. The Arabic word denoting these norms and behaviours is *adab*. The term refers to prescribed Islamic etiquette: good manners, refinement, morality, decorum, humanness and decency.[23] This set of core values derives from the Greek *eukrasia* ('balance'), and it has been translated and strengthened as the Quranic concepts of 'moderation' and 'symmetry.'

Islām has rules of etiquette and an ethical code covering every aspect of life, included cure, care, healing and dying. The spiritual dimension contributes as much to the healing process as the physical one. This unitary vision is evidenced by the approach of Muslim scholars to the treatment of pain and illness, which should protect both the spiritual and material spheres of the person. The physical sphere has recourse to medicine, drugs, surgery, etc.; in the spiritual one there is an attempt to restore the patient's bond with the Creator through prayers and reading of the Qur'ān, the *ḥādīth* and specific supplications.[24] Spiritual healing is still fairly widespread in Saudi Arabia, together with traditional healing practices, which can be found together with modern medical therapies. Traditional practices may include the use of *Zamzam* water, obtained from the well in the Holy Mosque located in Makkah,[25] or the use of honey and nigella seeds (cumin). Cauterization is a traditional healing method still practised by some Muslim doctors, despite the fact that it was not particularly recommended by the Prophet.[26]

The spiritual aspect of health-care is explicitly revealed by the fourteenth-century historian Abū 'Abd Allāh Muhammad ibn Ahmad al-Dahabī, the great Shafiʿī, *aḥādīth* scholar and historian of early Islām, born in Damascus in 673/1274:

> It is obligatory for every Muslim to seek nearness to God with whatever means possible by way of service to Him and that he try his utmost to carry out God's commands and ordinances. Now, after carrying out specific religious rites and desisting from actions He has prohibited, the most beneficial means and the most helpful service rendered to God is that which benefits man in preserving his health and in curing his illness, since health is something Muslims are asked to pray for even in their ritual prayers.[27]

Another ninth-century author, Ishāq ibn 'Alī al-Ruhāwī, in his most celebrated work, *Adab al Tabīb* (literally "Morals of the physician"; roughly translated as 'Practical ethics of the physician,' or 'Practical medical deontology'), wrote:

> The philosopher can only improve the soul but the virtuous physician can improve both body and soul. The physician deserves the claim that he is imitating the acts of God and the exalted as much as he can.[28]

Adab al Tabīb is divided into twenty chapters, each dealing with a specific aspect of medical ethics. They fall into three general categories: the conduct of the physician, the conduct of the patient, and the conduct of the public at large towards the medical profession and its patients. The text covers a physician's personal beliefs and practices. It places great importance on his/her faith in God and personal health and hygiene, as well as his/her manner with colleagues, nurses, and patients.

Incorporating themes and direct quotations from Greek philosophers such as Aristotle, Plato and Hippocrates and from the Roman physician Galen, al-Ruhāwī writes that doctors should be placed high in the social hierarchy, with remuneration sufficient for them not to be forced to take other work, although he instructs doctors not to flaunt their wealth. According to al-Ruhāwī, the fees charged to rich patients should be enough to cover the expenses of poor patients who cannot pay for themselves.[29] On the one hand, the symbiosis between the physician and God (the physician imitating the acts of God) constitutes an ethical framework in which it is important for Muslim doctors to develop a virtuous deontology that becomes their second nature and is inspired by the Qur'ān and the *Sunna* of Prophet Muḥammad (*aḥādīth)*. On the other, the patient comes to rely on a sense of public welfare among physicians (who waive their fees for poor patients or charge different fees for rich and poor patients) which later drove the growth of clinics and hospitals "which were endowed by wealthy individuals or by royal patronage as an expression of moral commitment for the benefit of the indigent … thus health care evolved out of Islamic values and spawned a distinctive set of moral concerns that led to institutions for the public good."[30]

Modern clinical and diagnostic technologies are not merely 'neutral' or mechanical components; they can be likened to 'cultural artifacts,' and they should be considered as resulting from the crystallization and fertilization of conceptions, mentalities, implicit and traditional values, characters, and ideals of the culture that produces them.[31]

The explosion of medical technology and the means to cure certain major diseases began between the late nineteenth and early twentieth centuries. The electronic boom also led to a dehumanization of medicine and obscured the need to provide a supportive and caring environment for patients with chronic illnesses.[32] Despite its undeniable benefits, the 'new' scientific medicine of testing and diagnostic precision stood in tension with the 'old' medicine of compassion and care. Obviously, thanks to advances in public health, medicine substantially reduced deaths from various diseases (e.g. infectious ones) and dramatically extended life expectancy for the masses. Yet, while doctors were saving lives from diseases that only a generation before could have been mortal, an increasingly biomedical focus on disease threatened the care of the patient.[33] It was only in the 1960s that the importance of giving equal consideration to the patient's spiritual, psychological and physical dimensions became part of the public debate. At the same time, the paternalistic relationship between a patient seeking help and a doctor whose decisions were silently complied with by the patient, started to be replaced by a more autonomous, active, and thus patient-centred role in which "the physician tries to enter the patient's world, to see the illness through the patient's eyes."[34]

The doctor-patient interaction in a traditional society[1*]

Doctor-patient communication is still the core of the 'art of medicine,' and it constitutes a prime ingredient of the complex patient-physician relationship. Various studies have demonstrated that physician-patient communication has a significant influence on the outcomes of patient care, including patient satisfaction, compliance with treatment, recall and understanding of medical information, coping with disease, and even the actual state of health.[35]

Doctor-patient communication is a skill essential for satisfaction of the patients' needs and expectations, and it becomes crucially important in the case of serious diseases like cancer. In a conservative Islamic society like that of Saudi Arabia, considerable effort should be made to ensure confidentiality and sensitivity to patients' feelings as well as those of their families in communication between the doctor and the patient.[36] Such communication may be problematic in a country like Saudi Arabia, which has a rather large number of foreign personnel (either Westerners or Arabs from different MENA countries) employed in hospitals and health services.[37] These workers communicate with patients and with each other in a variety of languages or Arabic dialects different from the local one. Moreover, they are given little guidance on local traditions and the prevalent health-related beliefs and culture.[38] Patients should be examined with extreme (Islamic) ethical sensitivity and awareness of local social traditions. For instance, if a doctor asked an unmarried American or European woman if she has children, she would most probably answer without any hesitation or embarrassment. However, if the doctor put the same question to an unmarried Saudi Arabian woman, she would inevitably take great offence because extra-marital relationships are strictly forbidden. Likewise, a male doctor examining a female patient requests the presence in the room of a third party – either a female nurse or a close relative – to avoid problems. Women in strictly Muslim communities like Saudi

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[1*] The following sections are based on field research conducted at the King Faisal Specialist Hospital and Research Centre Palliative Care Unit in Riyadh in 2014.

Arabia are more reticent in sharing their problems with male doctors because Islamic teachings advise women to appear unveiled only to other women and close male relatives unless it is absolutely necessary. Gender roles and responsibilities are distinct in Saudi Arabia culture. Cross-gender interactions may be more awkward, so that the presence of a female clinician is more acceptable and appealing to Saudi women (or a male clinician with a male patient).[39] Another gender-related issue which may affect the behaviour of patient and physician is the lack of complete privacy during the medical consultation. In Saudi culture, when a female has a medical problem she is accompanied by a very close relative or her husband, who will do all the talking and interpretation, especially when the physician is a male.[40] This may be a major obstacle to building empathy and trust between patients and physicians. Empathy and trust are important in any doctor-patient relationship, but they can become crucial in palliative care and end-of-life care treatments. Not only have many studies established a link between patient's trust in the physician and his/her improved health status, but some (male) palliative care doctors in Saudi Arabia reported being extremely cautious in dealing with female patients and their families, avoiding verbal and non-verbal behaviours that might provoke a cultural clash. Comforting patients and their families when they are distressed by holding a patient's hand or briefly touching a member of the patient's family in a moment of anguish is not necessarily always welcomed or appreciated in a culturally sensitive country like Saudi Arabia. In all cultural contexts, physical touch and patient modesty is an integral part of the healthcare provider/patient relationship. Physicians and nurses consider touching the patient to be an 'instrumental' or task-orientated touch, as identified by Watson.[41] However, even though Arab societies are 'contact' cultures,[42]

> touching tends to be among the same sex and within families. Although men are often observed walking hand in hand down the streets, men and women never touch in public, as touching the opposite sex is considered offensive.[43]

This sometimes creates problems for physicians and nurses unfamiliar with Saudi culture when patients or families are given bad news, because they are not able to 'touch' or 'comfort' in the usual way. Modesty is an important issue, and it is held in high regard by both males and females in Arab culture.[44]

Family and kinship ties, cultural and religious influences are all key factors to be considered in care provision. The beliefs and practices of patients who follow Islām in a conservative country like Saudi Arabia may have an effect on the patient's health care in ways that are not apparent to many health-care professionals and policy-makers internationally. Family involvement can be a major contributor to the patient's emotional, social and psychological well-being. Family members – mainly the closest male relative – are viewed as the principal decision-makers as they often 'dictate the care,' including the extent of the care to be given; palliative care physicians frequently discuss major ethical decisions with patients *and* their families.[45] A palliative care physician at the King Faisal Specialist Hospital and Research Centre in Riyadh reported how, for example, resuscitation is an issue more for the family than the patient him/herself, who almost never discusses the matter with doctors.

Palliative care in Saudi Arabia

Saudi Arabia is a vast country, and the attitudes of patients to medicine can vary widely according to their area of residence, level of literacy, age, gender, and social status. There are about 25 million Muslims in Saudi Arabia, or 97% of the total population. However if foreign workers are excluded, about 100% of the country's population is Muslim. About 85–90% of Saudis are Sunnites, while Shiites represent around 10–15% of the Muslim population.[46] Therefore, delivery of quality healthcare to Muslim patients requires health professionals to gain greater awareness of the religion of Islām, given that every terminally ill Muslim patient, like every patient, is unique. Moreover, not only do the schools of thought vary, but also the level of observance may differ considerably among patients within the same school of thought.

Physicians and health-care professionals in general should adopt cultural competence and sensible awareness when caring for (Muslim) patients and dealing with their family members. A holistic approach to health care requires staff to understand Islamic belief, religious practice, spiritual beliefs, cultural mores, and social background.[47] Communication and mutual trust and respect are the means to achieve the most effective medical treatment. Spiritual history and social background are vital for delivering holistic care successfully, and for ensuring a better quality of life for the terminally ill patient and his/her family.

Palliative care is an emerging multidisciplinary health and social care area which received definition in the 1970s. It is concerned with improving the quality of life, symptom management, and the psychological, social and spiritual care of people with advanced disease, whatever that disease may be.

Palliative care was first introduced in Saudi Arabia in 1992 at the King Faisal Specialist Hospital and Research Centre in Riyadh. The idea of developing a palliative care programme started to circulate in the late 1980s when a group of American and British nurses reported the need for specific management of patients with very advanced cancer and those near the end of life. Dr. Isbister, a surgeon who took up the call of these nurses and also saw the need to treat symptomatic terminal patients, discussed the matter with the hospital authorities. The hospital's chief executive officer asked Dr. Isbister to explore the possibility of inviting an authority on palliative care to visit Riyadh to give advice. Dr. Derek Doyle from St Columba's Hospice agreed to visit, and as a result of his report, a palliative care service was established at the hospital in 1992.[48] Over the years, chronic-pain patients have also benefitted from the programme besides advanced-cancer patients. The unit started with two beds and expanded to a ten-bed facility in 1995.[49]

Interestingly, the palliative care service began with home health care provided mostly by Western nurses and Western physicians who sought to import their experience of palliative care gained in the English-speaking countries to the Kingdom. The pilot project began with a start-up programme for twelve patients with advanced cancer. At the end of the trial, nine of the twelve patients were able to die in their own homes surrounded by their families without any forced hospitalization; also the number of visits to ER during the palliative care programme was dramatically reduced compared with other terminal patients.

Consequently, there was evidence that a palliative-care based programme had a positive impact on diverse aspects of the quality of life of patients with advanced cancer and their families. The fact that the first care providers were Westerners was initially seen as a potential constraint on the project's development. Fears of nurses and physicians unable to communicate properly in Arabic and in the context of the patients' emotional and cultural circumstances,[50] and the reluctance of Saudi patients and families to open their homes to foreigners, were soon dissipated. Translators/drivers were hired to take the Western female nurses to the patients' homes. At the end of the day, the physician consulted with the nursing staff, and afternoon visits were made if necessary.[51] A questionnaire distributed at the end of the pilot programme revealed very positive responses from the patients' families.

In 1999 the European School of Oncology sponsored a symposium at the hospital. During the symposium a workshop was organized to address the problem of the availability and distribution of narcotics to patients with advanced symptomatic cancer.[52] Obstacles to the goal of achieving pain management protocols proper to advanced cancer patients were identified. The non-recognition of pain management programmes by health and religious authorities was a major problem. Patients themselves were reluctant to report pain or to take analgesic medications, particularly morphine; they considered pain management not to be a priority with respect to other components of care, or as unacceptable according to their religious beliefs.

It was suggested that the issue of the religious acceptability of the appropriate use of pain-relieving drugs in patients with advanced cancer should be put to the Committee of the Leading ʿ*ulamāʾ* (Council of Religious Scholars). A year later, the *muftī* general and President of the Committee of Leading ʿ*ulamāʾ* issued a *fatwā*. It stated that there was no objection to using these analgesics (opium and other analgesics) in advanced cancer patients because they were considered a necessity.[53] The *fatwā* issued by the religious authorities condoning the use of morphine in patients with advanced cancer was a decisive step. Chronic pain, particularly as it occurs in terminal cancer, has several distressing features: it grows progressively worse; it creates a feeling of hopelessness and despair in the patient and his/her family; it dominates the patient's life; and it seriously compromises the patient's quality of life.[54]

> One part of pain is its perception, the other the emotional response to it. This is why people experience different degrees of pain. Pain is precisely what the patient says it is, and hurts as much as they say it hurts. Pre-conceived ideas of how much pain patients will or should have, are best avoided. There is a general lack of knowledge of pain relief in the Kingdom, and in many hospitals adequate analgesics of the morphine type are simply not available. There is an unreasonable fear of morphine addiction amongst patients and their families, but studies have convincingly shown that addiction is never a problem in a terminal illness.[55]

Pain management is crucial for reducing patients' distress and increasing productivity and functioning. A WHO study has revealed that individuals who live with chronic pain are four times more likely to suffer from depression or anxiety than those without pain. Chronic pain is linked with physical, psychological and social consequences, and can be regarded as a disease entity *per se*.[56] The KFSHRC cooperates with a narcotics pharmacy located inside the hospital and directed by a trained pharmacist. Through this cooperation, the Palliative Care Department is able to ensure adequate supplies of oral and parental morphine and transdermal fetanyl patches.[57]

The centre now comprises an intensive ten-bed management unit, a consultation service, outpatient clinics, and home healthcare programmes. The Palliative Care team – now directed by Dr. Moḥammed Zafīr al-Shahri – consists of physicians, nurses, social workers, dieticians, physical therapists, home healthcare nurses, a unit translator, pharmacists, health educators and psychiatrists.[58] Dr. Shahri has also developed a fellowship programme and an advanced course for specialized physicians which includes theoretical and clinical components related to palliative care. Candidates eligible for the fellowship are graduates from accredited medical colleges and board-certified in a major specialty, preferably family medicine, internal medicine, anaesthesiology or general surgery.

For some time, the Palliative Care Unit at KFSHRC also had a spiritual counsellor. The service was suspended mainly for budget-related reasons, even though religious figures can always visit patients if needed. The majority of in-patients at King Faisal Hospital are Saudis, and consequently Muslims. Therefore a full-time spiritual advisor is not on the priority list at present, even though there are plans to hire a religious authority in the future to tend to the spiritual needs of patients. Staff is always available to help patients on such matters as well, but the non-Islamic staff often does not have the necessary background to reassure patients from a faith point of view.[59]

> Religion and faith, as practiced in a specific culture, acknowledge both hope and limits, and thereby assist the patient struggling to find meaning in the experience of suffering and death. The physician who understands something about his/her patient's cultural background may gain an added dimension of comprehending his/her patient's plight. In this way, more effective bonds can be formed which, in turn, will help the physician to better guide patients' choices.[60]

In Western culture, spirituality is a broad belief system and does not necessarily coincide with religion; a person can be spiritual without automatically subscribing to a specific faith, belief, or religion. In Islamic culture – as stated above – there is no spirituality without religion. Spiritual and religious beliefs are intertwined by culture.

In Muslim society, religious affiliation involves social elements, so that one can only marginally refer to 'spirituality' when talking about specific customs, folk medicines and traditional therapies.

Disclosing the diagnosis: cultural constraints and religious obligations

An essential aspect of palliative care is how health care providers understand the concerns of the patient and family and communicate these concerns to all those involved in the decision-making process. The principles used by ethicists include preservation of the patient's faith; sanctity of life; alleviation of suffering; respect for the patient's autonomy while achieving the best medical treatment without harm; and always being honest and truthful in giving information.[61] Discussing end-of-life issues is of major significance for terminally ill cancer patients and their families, and a difficult topic for both health professionals and patients and caregivers. Cancer is not only a disease, it is also a sequence of experiences that intensely affect the person involved.[62] The medical team should keep a number of things in mind when working with a Muslim patient. It should inform the patient of the diagnosis and prognosis, but should not give a specific estimated life expectancy at any point, since life is in the hands of God, not in those of the physicians.[63] As regards disclosure, telling lies is considered a great sin by the Islamic faith. The Prophet said "the signs of a hypocrite are three: whenever he speaks, he tells a lie; whenever he promises, he breaks it; and if you trust him, he proves to be dishonest."[64] What patients and families need from palliative care physicians is time. Time is a crucial issue, and patients and families need time to give true informed consent after evaluating the advantages and disadvantages of the treatment proposed. Patients and their families need to have time allocated to discussion during their visits with the treating physician so that they can talk about their worries and build a strong trust relationship with the latter. This also allows the patients to participate more fully in and cooperate with the treatment, and with such compliance improve the chance of success.[65]

> In Saudi Arabia, the predominant principle is 'beneficence,' where the patient is viewed as a member of a larger family that is responsible for the patient. The consent for the patient's treatment is usually a substitute consent by the family, whose purpose is to avoid disturbing the patient emotionally. Thus the family considers it a duty to protect the patient from harm. Telling patients the truth would impair their ability to cope with the situation and they may consequently lose hope.[66]

The issue of disclosing the truth about the illness can become even more complicated if the patient is a female. Saudi citizens are very dependent on their families, particularly females. This is mostly related to cultural values, not necessarily to Islām. Saudi society is generally characterized by a rather strong paternalism, close family ties, and marked traditions. All decisions are family-centred. Consequently, physicians in many Middle Eastern countries need to establish a physician/family affinity in addition to the physician/patient relationship. Sometimes the need to 'genderize' a relationship with a female patient arises, and the male physician will – for example – ask a trained nurse (if a female physician is not available at that precise moment) to collaborate in examination of the patient.

One of the reasons for the conservative attitude toward disclosure relates to the nature of the disease-cancer, which is still perceived by many societies in the Middle East as a death sentence. To be noted is that in Saudi society cancer is believed to be a protracted illness causing great disability and suffering that finally leads to a painful death. Cancer is therefore not the preferred word to use, and euphemisms, such a 'growth,' 'lump' and 'that disease,' have been developed by patients and families as alternatives. Consequently, even though truth-telling is a compulsory medical and Islamic ethical necessity, some physicians choose to avoid the word 'cancer' and substitute it with 'malignancy'; or they use the expression 'supportive care' instead of 'terminal treatment.'

The word for tumour in Arabic is *waram,* which has the same meaning as tumour used to have in English - i.e. a 'swelling.' The term does not specify the entity of the disease, whether benign or malign. Most patients seem to assume that the tumour ('swelling') is a benign disease. The word for cancer is *sarataān,* which means 'crab.'

The general consensus among PC physicians at the KFSHRC, however, is to speak language that the patients and their families can understand. It is important for patients to be adequately informed about the nature of their illness and to understand that 'no cure' is not the same as 'no care.' Once patients have built a strong trust bond with their physician, they are more likely to cooperate with the proposed treatment: total care personalized to each patient according to his/her needs. There is now ample evidence that patients cope better with a serious illness if they are informed. Approximately 50% of Saudi patients (and families) accept the diagnosis from the first visit; another 20-40% agree after the second consultation to start a PC treatment as soon as possible; 10 to 20% of patients refuse to accept the unfavourable prognosis and decide to travel overseas at considerable cost, and with the unrealistic expectation of a cure.

Problems occur when the patient's family – whose purpose is to avoid disturbing the patient emotionally – clashes with the doctors' precepts. In this way, the family feels that it is protecting the patient from harm by making efforts to secure his or her well-being and ensure that the patient is treated in an ethical manner (beneficence).[67] Withholding the correct information on the patient's health is possibly more a historical than a cultural peculiarity. The same approach prevailed until very recently in practically all other countries. Saudi Arabia is certainly a rather conservative country, and a general concern to preserve Islamic values and traditions is still very much present. Nonetheless, families of terminally ill patients are slowly starting to realize that granting the right of patients to be aware of their illness allows them to cope much better with the cures, and is compatible with the responsibility of the family to care for them.[68]

Patients generally tend to react badly to certain verbal and non-verbal messages emitted by others regarding their current illness and their potential death. By contrast, open communication with family members and the treating physicians is considered a factor alleviating their anxiety and stress and an important means to help them accept their condition, which was initially perceived as very difficult and as a kind of shock.[69] As mentioned earlier, however, patients need to have more time allocated to discussion with the treating physician during their visits so that they can discuss their worries.

Afterword

Palliative care is an approach that improves the quality of life of patients and families suffering the distress caused by a life-threatening illness. Early identification and prevention are actions important for the better assessment and treatment of pain and other physical, psycho-social and spiritual problems. Besides screening and early diagnosis (in a region known for very late cancer diagnoses), another essential requirement is spreading awareness among the population. Palliative care is still sometimes confused with euthanasia in Saudi Arabia, as well as in many other countries in the world.[70] The two concepts are completely the opposite to each other. Palliative care is the moral and ethical alternative to euthanasia.[71]

At the same time, it is also necessary to raise awareness among policy-makers: education and research remain important at many levels. In 2013 the Saudi Society for Palliative Care was established, and in 2014 there were thirty qualified Saudi physicians and one nurse with a specific PhD curriculum. One of the major endeavours for palliative care in the future is to assure the availability of palliative care services and medications throughout the Kingdom of Saudi Arabia. Besides the KFSHRC in Riyadh, which provides PC to patients who live outside Riyadh with a PC outpatients clinic follow-up programme, other PC providers in the Kingdom are: the King Abdullah Medical City in Riyadh and Jeddah; the Military Hospital in Riyadh; the North West Armed Forces Hospital in Tabouk; the Saudi Aramco Hospital; the King Fahd Medical City in Riyadh; the King Fahd Specialist Hospital in Dammam and the

King Abdullah Medical city in Mekkah.

Cultural aspects of life in the Middle East – especially strong family bonds, the acceptance of death, and the emphasis on religious values – may in fact play a decisive role in enhancing or promoting palliative care in the region.[72]

The development of palliative care programmes and facilities in Saudi Arabia, as well as in many other traditional societies, is likely depend on the cultural constraints that characterize Saudi society and that should not be overlooked. The extended family model remains a social norm in Saudi Arabia and in many other traditional societies. Even though nuclear families are on the rise – especially in large cities like Riyadh – kinship-group families are still numerous. In such extended families, it is considered the social duty of the family to care for dying relatives until the end of life. In Saudi Arabia, for instance, the very few geriatric-care structures that exist are commonly stigmatized by the community as homes for abandoned elderly.[73] It comes as no surprise, therefore, that palliative care centres are often labelled 'death homes.' At the same time, families who consider geriatric-care facilities negatively have no problems in admitting an elderly relative to a hospital or a tertiary structure. According to Dr. Shahri, "hospitals are viewed more positively because of the hoped-for outcome expected for them (namely, improved health), while geriatric care (or palliative care) facilities are viewed negatively because of the feared outcome associated with them (namely, death)."[74] This attitude greatly impedes the appropriate utilization of palliative care facilities by the community, together with the possibility of establishing stand-alone palliative care structures in the Arab region.

Notes

1 *ḥādīth* (pl. *aḥādīth*) refers to the record of the traditions or sayings of the Prophet Muḥammad, revered and received as a major source of religious law and moral guidance, second only to the authority of the Qur'ān. It might be defined as the biography of Muhammad perpetuated by the long memory of his community with its exemplification and obedience. The development of *ḥādīth* was a vital element during the first three centuries of Islamic history, and its study provides a broad index to the mind and ethos of Islam (Ecyclopaedia Britannica). Each *ḥādīth* is based on two parts, a chain of narrators reporting the *ḥādīth* (*isnad*), and the text itself (*matn*). *aḥādīth* are still regarded by traditional Islamic schools of jurisprudence as important tools for understanding the Qur'ān and in matters of jurisprudence (Gordon Newby, *A Concise Encyclopedia of Islam* (Repr. ed.), (Oxford: Oneworld 2002); Ahmad Ibn Hajar, *al-Nukat ala*

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